# THE LIVED EXPERIENCE OF PELVIC ORGAN PROLAPSE IN SAUDI ARABIA: AN EXPLORATION OF THE PERSPECTIVES OF SAUDI WOMEN LIVING WITH PELVIC ORGAN PROLAPSE.

## "I am really embarrassed to say these things to anybody, its private."

Thesis submitted in the fulfilment for the degree of

Doctor of Philosophy

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20 June 2022

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#### Statement 1

This thesis is being submitted in partial fulfilment of the requirements for the degree of PhD

#### Fahda-MHS

#### Statement 2

This work has not been submitted in substance for any other degree or award at this or any other university or place of learning, nor is it being submitted concurrently for any other degree or award (outside of any formal collaboration agreement between the University and a partner organisation)

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#### Acknowledgements

This thesis would not have been completed without the support of my supervisors. I would like to express my deep appreciation to Dr Sally Anstey, Dr Anna Sydor, Dr Rebecca Hemming, and Dr Catherine Dunn for their constructive academic supervision and valuable advice, guidance, and encouragement throughout my PhD journey. A special thanks to Dr Philippa Coales who was in the supervisory team for few months but contributed so much before we lost her to COVID.

I would also like to extend my appreciation to the staff at the school of Healthcare Sciences at Cardiff University. Many thanks to the PGR director Professor Ben Hannigan for being there whenever there was a need for support, and also to our previous program director Dr Tina Gambling who also sadly passed away.

This research was funded by Umm Al-Qura university; I am deeply grateful to be a part of this institution. I am also thankful to Jilly Bond for her contribution and to Dr Samira Albasri who was welcoming to provide me with help and support for accessing participants.

This research is the product of my dedicated work, I would not be able to be fully committed to it without the support of my family who were always there when I needed them. My dear parents, my beloved husband, and my amazing sisters, thank you for being so understanding and patient.

## Dedication

To my adorable three children: Battal, Turki, and my baby girl Talia who was born two months before my thesis defence.

#### Abstract

#### Background

Pelvic organ prolapse (POP or prolapse) is a commonly discussed topic in international literature but appears to be under-researched in Arab and Islamic societies, specifically in Saudi Arabia. Moreover, there are no national-level prevalence data sets and anecdotal evidence suggests that women delay seeking professional support until later stages of the condition when physiotherapy management is no longer efficient. Additionally, the hospitals particularly in the western province of Saudi Arabia, are not equipped with resources for women's health physiotherapy service provision. Previous literature suggests that culture shapes the experience of POP. Hence, this study was conducted to provide an indepth exploration of the lived experience of Saudi women with POP.

#### **Research process**

Participants were recruited from one of the governmental hospitals in the western province of Saudi Arabia. Women attending urogynaecology clinic were invited to take part in the study if they had a vaginal protrusion, sense of heaviness, or previously confirmed POP that has not been surgically managed. Semi-structured interviews with women (n=8) were conducted and then analysed using reflexive thematic analysis.

#### Findings

The analysis of women's experiences with prolapse generated five themes: the conceptualisation of prolapse, social support provided by family, the physical implications of prolapse and its effects on marital relationship, the healthcare seeking behaviour of women with prolapse, and the role of Saudi Arabian culture in shaping the experience of prolapse. Women had no previous knowledge about prolapse but understood it to be normal to ageing, frequent childbirth, housework, and early marriage. Approaching other women in the family was the first thing women did after experiencing the symptoms and various forms of support were received. The physical symptoms of prolapse altered women's body image perception and affected their intimate lives but it was only perceived to be

problematic if it was concerned with husband. Women chose to delay seeking professional help despite being bothered by the symptoms. Their healthcare seeking behaviour was affected by a wide range of factors; some acted as triggers or barriers to seeking healthcare support. Lastly, the analysis of the study data revealed that the Saudi Arabian culture has greatly affected womens' experience with prolapse.

#### Conclusion

The study has contributed to new knowledge and understanding about the experience of Saudi women with prolapse. The life world of women in Saudi Arabia impacted every aspect of their lives and it shaped their experience of the illness in addition to their healthcare seeking behaviour. The Saudi Arabian culture and the social norms were an overarching theme that fed into the themes generated from the analysis. The findings of this study have valuable implications for women, women's health physiotherapy service provision, and the healthcare system in Saudi Arabia.

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## **Glossary of Abbreviations**

DYSQ	Sexual dysfunction questionnaire
GP	General Practitioner
НСР	Healthcare professionals
IPA	Interpretative Phenomenological Analysis
IUGA	International Urogynaecology Association
МоЕ	Ministry of Education
МоН	Ministry of Health
МоІ	Ministry of Interiors
MRI	Magnetic Resonance Imaging
NHS	National Health Service
РНС	Primary healthcare
PIKQ	Prolapse and incontinence questionnaire
PISQ	Prolapse/ incontinence sexual questionnaire
POP/ prolapse	Pelvic organ prolapse
РОРРҮ	Pelvic organ prolapse physiotherapy
POPQ	Pelvic organ prolapse quantification system

PQoL	Prolapse quality of life
RTA	Reflexive thematic analysis
UI	Urinary incontinence
WHO	World Health Organisation

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#### **1. Chapter One: Introduction**

#### **1.1. Introduction**

The focus of this thesis is to explore and understand the experience of Saudi Arabian women with pelvic organ prolapse. This chapter discusses the rationale for the study and the gap in the literature that this research sought to address. It sets the scene for pelvic organ prolapse in relation to the aetiology, prevalence, and management. It also highlights the research questions, study aim and objectives, and provides an overview of the study design. Finally, this chapter briefly discusses the contribution of the findings to new knowledge and lays out the structure of the thesis.

#### **1.2.The rationale for the study**

Pelvic organ prolapse (POP) is a health condition affecting women that leads to the descent of one or more compartments of the pelvic floor (Dietz 2008). The condition is reported to affect women around menopause, causing them to experience a range of specified physical symptoms such as vaginal bulging, pain, bleeding, and pelvic pressure (Vergeldt et al. 2015). It is reported that the symptoms of prolapse are disturbing to women and affect their quality of life (QoL) (Digesu et al. 2005). Evidence suggests that the experience of POP is socially constructed and shaped by the cultural context (Gjerde 2017; Shrestha et al. 2014). Saudi Arabia is one of the countries where the topic of POP is under-researched. The reason for that is unclear but it could be informed by the cultural sensitivity of sexual related health issues in Saudi Arabia (Alomair et al. 2020).

I am a qualified physiotherapist from Saudi Arabia. Clinical trials have demonstrated that physiotherapy plays a critical role in the management of POP (Hagen et al. 2017; Stark 2012), but from my personal experience, the service is not sufficiently utilised in Saudi Arabia for women with prolapse. The Healthcare system in Saudi Arabia is equipped with resources relevant to the surgical management of the condition. However, it is noted that physiotherapy services often are neither provided nor sought by patients or other healthcare professionals for women with prolapse. In addition, based on my clinical practice and discussions with other healthcare professionals (HCPs) involved in the management of POP in Saudi Arabia, such as physicians, physiotherapists, and nurses, it is observed that Saudi women often delay seeking professional support until they are at an advanced stage of the condition. This means that those women with lesser symptoms do not get support to improve their symptoms. Indeed, anecdotal evidence suggests that a small number of women are seen seeking professional support in urogynaecology clinics but at late stages of prolapse where surgical management would be suitable to manage the symptoms.

This thesis will explore the experience of Saudi women with prolapse. Exploring the experience of POP will contribute to our understanding of the personal and social dimensions of the condition in Saudi Arabia that is necessary to be understood given the sensitivity of sexual health related topics in the context. This will perhaps aid in improving healthcare service provision for women with POP through identifying the needs of women with prolapse particularly from healthcare.

#### 1.3. Pelvic organ prolapse -Setting the Scene-

The international urogynaecology association (IUGA) has defined pelvic organ prolapse as the descent of the vaginal wall: anterior or posterior, the uterus, or the apex of the vagina that results from inadequate pelvic floor muscle support (Bureau and Carlson 2017). Weakness of the pelvic floor muscles is reported to lead to the descent of pelvic organs because the power of the muscle that hold pelvic organs in their normal position is diminished (Thomson et al. 2014). As pelvic floor organs, such as the uterus, bladder, or vagina are attached to pelvic floor muscles, it can be understood that the weakness of the muscles would result in the prolapse of one or more of these organs. The common reported symptoms of prolapse predominantly are the sense of vaginal bulging, pelvic pressure, and a sense of heaviness (Paul et al. 2019). Bleeding, vaginal discharge, recurrent infections, lower back pain, and urinary symptoms are also often reported in the presence of prolapse (Durnea et al. 2014).

The Pelvic Organs Prolapse Quantification System (POP-Q) is reported to be the standard method for the assessment and reporting the severity of prolapse, and it

has been widely used in clinical research (Treszezamsky et al. 2010). Nevertheless, POP-Q assessment requires substantial training and it is noted that it can only be appropriately administrated by a specialised HCP; therefore, it has been criticized for being overly comprehensive and difficult to be understood even among HCPs (Manonai et al. 2011). Using POP-Q (Figure 1) to assess the severity of prolapse by determining the anatomical stage of the descent, prolapse is assessed in centimetres relative to the hymen, and these assessments can be translated into five ordinal stages which are from 0 to 4, with stage 0 representing no prolapse.

Stages of POP-Q system measurement

Stage	no prolapse is demonstrated
0	
Stage	the most distal portion of the prolapse is more than 1 cm above the level of the hymen
1	
Stage	the most distal portion of the prolapse is 1 cm or less proximal or distal to the hymenal plane
2	
Stage	the most distal portion of the prolapse protrudes more than 1 cm below the hymen but protrudes no farther than 2 cm less than the total vaginal length (for example.,
3	not all of the vagina has prolapsed)
Stage	vaginal eversion is essentially complete
4	

#### Figure 1: POP-Q System Measurement

Adequate staging of prolapse is of paramount importance in clinical practice and in research as it enables the evaluation of the anatomical outcomes following conservative or surgical treatments. However, it is observed that studies have used variable reference points to identify the anatomical failure or the threshold to define abnormal support to pelvic organs. Indeed, Gutman et al. (2008) further pointed out that the POP-Q system does not specify a threshold (stage or individual point) for the definition of abnormal support. Respectively, it is not clear how the data was derived to develop this tool as it relies heavily on the use of expert opinions.

Swift et al. (2005) indicated that prolapse is noted among 37% of women presenting for annual gynaecologic examinations using a definition of stage two or greater. However, many women with stage two support are asymptomatic, so it is not clear that a clinical finding of stage two support should be equated with a disease state. Thus, it can be stated that POP-Q does provide an indication of the

stage of the condition through physical assessment and clinical presentation, but it does not consider the severity and bothersome impact perceived by women. Indeed, the existing symptoms may not correlate with the prolapse stage because the point where prolapse becomes symptomatic varies across individuals. It is important to clinically assess the women, but this does not tell us much about their experience.

#### 1.3.1. Prevalence, aetiology, and risk factors

It has been observed that there is a disparity in literature reporting the prevalence of prolapse as the reporting rates range between 3 to 50% (Maher et al. 2013). The significant variation in the reported rates depended upon the definition utilised and examination based on symptomatic presentation. Nevertheless, it is often difficult to estimate the true prevalence as the condition often remains asymptomatic until it descends to the hymen ring, typically around the age of menopause (Bureau and Carlson 2017). Nevertheless, there are no exact figures, women do not report and even if they do their experiences may vary as per the discussion above.

In terms of Saudi Arabia, one recent study reported that the prevalence of prolapse is around 23% among Saudi women (Al-Badr et al. 2022). However, the wide age range of study participants, between 18 to 65, meant that only 14.6% of the women included in the study approached the age of menopause. This is critical because evidence suggests that prolapse is more often symptomatic around the age of menopause and due to factors related to hormone levels, younger women often do not experience the symptoms (Zong et al. 2010). Moreover, it is difficult to measure or estimate the true prevalence rate in Saudi Arabia because prolapse is currently an under-reported health condition as women often choose to seek professional support only at later stages; therefore, it could be suggested that the prevalence rate of 23% that is reported by Al-Badr et al. (2022) is an underestimate of the true rate.

Similar to prevalence, the aetiology of prolapse is poorly defined in literature particularly in terms of identifying the exact cause of prolapse, several risk factors have been linked to developing prolapse in literature though. It has been indicated that vaginal delivery is associated with an increased incidence of POP and the link is well-established in the literature (Dietz 2008). It is proposed that vaginal birth causes fascial defects, respectively, frequent vaginal deliveries lead to developing prolapse (Barbalat and Tunuguntla 2012). Another risk factor correlated in literature with vaginal delivery is the pudendal nerve trauma that may occur during labour and could lead to levator ani muscle impairment, which weakens the pelvic muscle support causing prolapse (Lubowski et al. 1988).

In terms of the pathophysiology of POP, long term follow-up studies have aided in the overall understanding of the condition. Studies using magnetic resonance imaging (MRI) (Delancey et al. 2017) and three-dimensional pelvic floor ultrasonography (Dietz 2008) have established the association between levator ani defects and prolapse, indeed, women with levator ani defects were at least twice as likely to show clinically significant prolapse (Giarenis and Robinson 2014). These findings further support the rationale that vaginal birth is a significant factor in the development of prolapse.

What is understood from literature in terms of the aetiology and risk factors of prolapse is that pelvic muscle weakness, particularly levator ani muscle weakness, is the main causing factor for developing prolapse. Levator ani muscle weakness could result from pregnancy and childbirth because the levator ani essentially is comprised of a group of muscles that sit on the pelvic floor and during labour these muscles are believed to stretch between 25 to 250% of their usual size (Dietz et al. 2008). Because levator ani is a skeletal muscle, it can be assumed that it would be susceptible to tear during birth as, physiologically, it is noted that most skeletal muscles rupture once they are stretched beyond 150% of their length (Svabik et al. 2009). This suggests that levator ani tears or trauma during labour may potentially be the most substantial risk factor for developing prolapse.

Ageing is another factor that has been repeatedly reported to cause prolapse. However, the presence of asymptomatic prolapse has been demonstrated in young women in a number of early observational studies (Swift 2000; Dietz et al. 2004). Linking age to the development of prolapse may imply that prolapse is an expected condition that occurs with ageing. Yet several authors have found minimal or no correlations between advancing age or oestrogen level and prolapse progression (Vergeldt et al. 2015; Trowbridge et al. 2007). The hormonal changes during menopause have been linked to prolapse because low levels of oestrogen are believed to reduce pelvic floor support (Zong et al. 2010). Nevertheless, it is argued that it is hard to make sense of this assumption as low levels of oestrogen would lead to tissue stiffness; hence, less severe prolapse would be expected to be seen with approaching menopause (Goh 2003). Age might not be the direct cause of prolapse, but it could adversely affect the condition if there has been a previous levator ani muscle tear or trauma during childbirth, leading to progression of symptoms with advancing in age.

#### 1.3.2. Management

#### 1.3.2.1.Conservative management

Prolapse at stages one and two is often asymptomatic; hence, it is reported that women often do not seek healthcare support until they experience bothersome symptoms indicating that they are at stage three or four anatomical prolapse (Thomson et al. 2014). Conservative treatment is the first line of management in mild to moderate prolapse depending on the clinical presentation and the experienced symptoms. Treatment plan includes lifestyle changes, ring pessary and supervised pelvic floor muscle training. It has been estimated that the majority of urogynaecologists use ring pessary as the first approach for the non-surgical treatment (Stark 2012). Indeed, ring pessary has been reported to be effective in managing prolapse related pelvic floor symptoms such as urinary difficulties or incontinence, quality of life, and body image perception (Fernando et al. 2006; Patel et al. 2010). However, it has been reported that nearly half of women discontinue pessary use within one year as side effects, such as bleeding, extrusion, severe vaginal discharge, pain and constipation are reported to occur in half of those treated and are the main reason for discontinuation (Sarma et al. 2009). This would suggest that pessary might not be sufficient to be used alone to manage prolapse symptoms. In Saudi Arabia, there is currently no evidence reporting the use of pessary for women with prolapse.

#### 1.3.2.2.Physiotherapy management

It has been presented above that weakness of the pelvic floor muscles "levator ani muscle" following childbirth is a critical risk factor for developing prolapse. Current evidence suggests that physiotherapy is integral in managing POP symptoms (Stark 2012). Improving the function of the pelvic floor muscles through pelvic floor muscle training (PFMT) would improve the support provided by the muscles to hold pelvic organs in place. Indeed, an observational study by Borello-France et al. (2007) indicated that weakness of pelvic floor muscles is a crucial factor contributing to the development of prolapse. Moreover, PFMT has been demonstrated to prevent symptoms of existing POP from worsening (Yamanishi et al. 2010; Piya-Anant et al. 2003).

Stüpp et al. (2011) also indicated a greater improvement in muscle function following pelvic floor muscle training sessions particularly if supervised by a trained physiotherapist. This was further confirmed by the Pelvic Organ Prolapse Physiotherapy or (POPPY) trial by Hagen et al. (2014) where individualised PFMT sessions provided by a specialised physiotherapist were provided to 225 women with symptomatic stages one, two, or three prolapse. Findings demonstrated a significant reduction in prolapse symptoms compared to 222 women in the control group who received prolapse lifestyle advice leaflet and no muscle training.

Despite the effectiveness of PFMT sessions provided by physiotherapy in the management of prolapse, the service is not routinely provided to women with prolapse in Saudi Arabia. From my personal experience, this is possibly because of two factors: women with prolapse who chose to delay or avoid seeking professional support, and the healthcare system that might not recognise the role of physiotherapy in the management of POP (see chapter 2). Hence there are a limited number of women's health physiotherapy specialists in hospitals, particularly in the western province of Saudi Arabia.

#### 1.3.2.3.Surgical management

There are multiple surgical methods for treating various types of prolapse, and there is a continuous debate among medical experts about the methods with the most desirable long-term outcomes (Maher et al. 2010). Most surgical procedures for prolapse are performed vaginally, for example, anterior or posterior vaginal wall repair where supporting sutures are placed into the fascia is to elevate the prolapsed bladder or rectum (Thomson et al. 2014). Alternatively, a suture of the vaginal vault to the body of the sacrum by use of a mesh (a synthetic or biological material used to reinforce) can be performed either through an abdominal incision or through a laparoscopy (Thomson et al. 2014)

Among women having undergone surgical correction for prolapse, it has been estimated that up to 30% require a second operation within five years (Thomson et al. 2014). The risk of prolapse repair revisions has been found to be higher in women whose initial hysterectomy was a result of prolapse and the risk is even higher if the initial prolapse was above grade two (Dällenbach et al. 2007). Several side effects have been reported to be associated with MeSH procedure such as vaginal exposure, persistent pain, and erosion into the urinary tract that often requires further surgical management (MacDonald et al. 2016), yet anecdotal evidence suggests that it is implemented in Saudi Arabia despite the range of complications associated with it.

Considering the greater complications and side effects from the available surgical management for prolapse, it is unknown whether Saudi women are aware of these issues when seeking support at later stages of prolapse. Hence, this further asserts the need for approaching Saudi women and gaining an understanding of their experience and knowledge.

#### 1.4.Justification for the study

The medical model of illness assumes that disease is universal and not affected by time and space (Conrad and Barker 2010). The current biomedical model adopted in the assessment and management approaches in Saudi Arabia views POP as a disease with universal symptoms and linear progression and might not recognise potential personal and cultural variation in the experience of the symptoms. This is of particular importance in terms of prolapse because it is a hidden and underreported condition in some societies including Saudi Arabia. As a physiotherapist, I believe that being involved in the management of POP whilst obtaining a biomedical perspective and using tools similar to POP-Q to assess the severity and progression of symptoms experienced by women with prolapse will not help in addressing their needs of healthcare rather it helps the HCPs to determine the appropriate management method based on the clinical presentation and assessment. Such assessment tools do not recognise the role cultural factors

may have in shaping the experiences of health conditions that are sensitive in the context. Women may present with stage four prolapse and behave as if they have mild symptoms because of the cultural sensitivity of the condition or vice versa.

This study seeks to fill a gap in the literature by exploring the experience of Saudi women with POP. It aims to identify the potential implications of the culture in Saudi Arabia in shaping the experiences. As a qualified women's health physiotherapist, this is aimed at understanding the womens' experience first and explore their needs of healthcare which might help in understanding how physiotherapy may fit within their experience. This will respectively be informative to the current healthcare system in Saudi Arabia in terms of fulfilling those needs.

#### **1.5.Research question**

What is it like for women around the age of menopause to experience pelvic organ prolapse in Saudi Arabia?

#### 1.6.Study aims and objectives

Aim: This study is focused on exploring the lived experience of pelvic organ prolapse of Saudi women around the age of menopause.

The objectives of the study are to:

- Explore if the culture in Saudi Arabia in shaping impact the experience of pelvic organ prolapse.
- Be respectful of the potential individuality and subjectivity of the experience due to the sensitivity and hidden nature of prolapse in Saudi Arabia.
- Provide recommendations for healthcare service provision based on the experience of women with prolapse through disseminating information so that other healthcare professionals can better understand womens' experiences.

#### 1.7. Overview of the research design

In order to address the study aims and objectives, a qualitative interpretative research study design was adopted. Using in-depth semi-structured interviews as a method of data collection enabled a deep engagement with the context. Interviews were conducted on a one-to-one basis with eight women around the age of menopause who were purposively sampled. The interviews were used to explore what is it like to experience POP in Saudi Arabia and gain an in-depth understanding of their sense-making. The reflexive thematic analysis approach undertaken to analyse study data revealed that Saudi Arabian culture greatly informed the women's experience of prolapse in every aspect.

#### **1.8.**Contribution to new knowledge

According to the research aim and objectives, and in view of the study findings and discussion (chapters seven and eight), this study contributes to new knowledge in theory and practice. It provides an understanding of the experience of prolapse in Saudi Arabia that is explained by the lifeworld theory by Husserl (1970). The recommendations developed based on study findings can be implemented by physiotherapists, healthcare professionals, and the healthcare system in Saudi Arabia to hopefully address the needs of women with POP. The details of these contributions are discussed in chapter ten.

#### **1.9.Structure of the thesis**

The study is organised and presented in ten chapters. Chapter one is an introductory chapter that informs the reader about the thesis's aim and objectives and set the scene for pelvic organ prolapse as a health condition requiring intervention. Chapter two provides contextual background about the study describing the life world of women in Saudi Arabia. In addition, it presents the healthcare system in the Kingdom and women's health physiotherapy service provision. Chapter three provides a scoping literature review that places the current study in the context of what is already known about the topic and provides justification for the investigation. Chapter four details the research design, focusing on methodological and theoretical perspectives. Chapter five outlines the research methods, including ethical considerations, sampling, recruitment process, data collection process,

semi-structured interviews, interview process, and practicalities. Chapter six presents a detailed description of data management principles and procedures, including transcription, translation issues, and analysis procedures. Chapter seven presents the study findings through describing and interpreting the participants' stories and experiences. Chapter eight discusses the findings within the context of the lifeworld. Chapter nine discusses the quality of this study as a qualitative research design in relation to Yardley's principles for dimensions of quality in qualitative research. Finally, Chapter ten explores the implications of the study for patients, the public, and healthcare practice, and outlines the limitations of the study and directions for future research.

#### 1.10. Chapter summary

In this first chapter of the thesis, the rationale of the study, research question and overview of the study design have been presented. The chapter has set the scene for the thesis through presenting pelvic organ prolapse as a health condition requiring intervention and the current management approaches while highlighting the role of physiotherapy. This chapter has also provided an outline of the thesis while the next chapter will present information about the study context, which is important to set the scene and guide the reader to understand the context in which this study was conducted and the world in which the participants live.

# 2. Chapter Two: Contextual Description of The Kingdom of Saudi Arabia.

#### 2.1.Introduction

This chapter will provide an overview of the Kingdom of Saudi Arabia so as to set the context for this study. Initially, the demographic and socioeconomic context of the Kingdom of Saudi Arabia will be considered, presenting the culture of the Kingdom of Saudi Arabia and reviewing the relevance of the religion of Islam to the Kingdom. As this is a study of Saudi womens' experiences, specific consideration will be given to females within Saudi Arabian culture and issues that are important to them. The latter section outlines the healthcare system and specifically women's health physiotherapy service provision in Saudi Arabia.

#### 2.2. The Kingdom of Saudi Arabia

The Kingdom of Saudi Arabia is the largest country in the Arabian Peninsula, occupying about 80 percent of the total land area (General Authority for Statistics 2015). Saudi Arabia has been the homeland of many ancient civilisations and cultures throughout history which made it a country with a valued location and a historical background for Muslims all over the world.

Economically, Saudi Arabia is one of the world's largest oil exporters, having approximately one-third of the world's oil reserves and the world's largest reserve pumping capacity for oil. It is believed that oil industrialization has paved the way for the government of Saudi Arabia in both social and economic development (Brown and Busman 2003). Indeed, this healthy economic profile has positively impacted the lifestyle of people living in Saudi Arabia and has increased the standards of living, shifting the socioeconomic status of Saudi Arabia towards wealth and modernisation of the country.

Access to healthcare and education is free to all Saudi citizens and the payable services in private healthcare and education sectors have always been tax-free for the citizens and non-Saudi residents of Saudi Arabia. This however changed in 2018 as the country adopted a 5% value-added tax as one of the mechanisms covered by the Kingdom's 2030 vision of reducing dependence on oil as a primary source and diversifying the sources of the economy to ensure financial balance, continuity of development, and sustainability of government services (Bogari 2020). The tax increased to 15% in 2020 following the Coronavirus Disease -19 (COVID-19) pandemic in order to mitigate the impact of the COVID-19 pandemic on the economy and maintain the economic status of the country (General Authority of Zakat and Tax 2021). This however does not affect the free healthcare and education services provided to citizens.

Saudi Arabia has recently announced a broad set of socio-economic reforms, known as Vision 2030, that aims to decrease Saudi Arabia's dependence on petroleum, expand the economy and improve several public service sectors as such education, health, infrastructure, leisure, and tourism (Vision 2030). Therefore, many public services and social changes are occurring to meet the vision of 2030, this includes agendas to empower Saudi women in the society.

#### 2.2.1. The religion of Islam and the culture in Saudi Arabia

The Kingdom of Saudi Arabia is an Islamic country. The Saudi nationals as per law must be followers of the religion of Islam. Non-Muslims are not given the Saudi Arabian national identity. Hence, it is a requirement to be a Muslim in order to have Saudi national identity. The influence of Islam on the social life in Saudi Arabia is inevitable given that Islam in essence is embedded in both policy and politics in the Kingdom. Essentially, the Islamic religion is the foundation of the Saudi Arabian law, working under the premises of Shari'a law. Indeed, the Saudi Arabian constitution applies justice and equality in accordance with Shari'a law regardless of gender (The Constitution of Saudi Arabia, 1992). This particular law, however, was not fully implemented by the Saudi Arabian society in the past and it resulted in women being disadvantaged in many aspects such as education and employment.

It has been stated that the modern culture in Saudi Arabia has been informed by the Islamic heritage of the country, the historical roles in the past which are connected, and the Bedouin traditions in the Kingdom (The Embassy of Saudi Arabia in Washington D.C 2021), and the religion of Islam is acknowledged to be a strong source of legitimacy for the Saudi Government (Alharbi 2015). As a Saudi national myself, it is observed that the daily customs and tradition in Saudi Arabia serve as a reminder of the importance of Islam, Arab culture, and traditions.

The social atmosphere of Saudi Arabia can be described to be conservative and reserved, however, levels of social conservatism differ between regions, tribes, and minorities in Saudi Arabia (Nevo 1998). The rural areas are considered more socially conservative than cities with heavy international exposure such as the city of Jeddah, Makkah, and Madinah. These cities are considered holy sites and are frequently visited by pilgrims from across the world and thereby have significant international influences (IES, 2021).

#### 2.3. Situating women in the context of Saudi Arabia

#### 2.3.1. Historic overview of lives of women in Saudi Arabia

It has been stated above that the constitution of Saudi Arabia applies justice and equality to all regardless of gender. However, the status of women in Saudi Arabia has been constantly changing due to the frequent variation in the regulations and economics of the Kingdom. This respectively informs the social norms in the country. There have been certain dramatic political events in Saudi Arabia that have shaped the status of women starting with the discovery of oil in the Saudi Arabian land in 1930 until the recently developed vision 2030. Historically, women were reported to be an important part of agricultural production in the Arabian Peninsula (Raney et al. 2011). It has been noted that the oil-generated revenues by the 1970s resulted in the wealth of the country in a short period of time affecting the structure of the society (Yamani and Allen 1996). By the year 1980, Saudi Arabia was described as a complex society determined to preserve religious identity and traditions and eager to advance on the socioeconomic level (Huyette 1984). Covering faces for women was not prevalent until 1980 as the events proceeding that time such as the fall of the Iranian shah and the uprising of Makkah led to increased conservatism in the Kingdom. Shortly after, in 1990, the Gulf War took place and as per Rajkhan (2014), this further challenged the society and placed more constraints on women to stay home.

Since then, the main roles of women in some societies in Saudi Arabia until recently have been limited to being housewives and nurturing family. As per religion and cultural norms, women in Saudi Arabia were not, and still are not, expected to provide their families with financial support because religion has emphasised the role of men in providing protection and support to women; a law defined as guardianship. It is argued that these patriarchal ideologies have been fed with the concept of protecting women in terms of the power structure of the family, particularly in the husband-wife relationship (Velayati 2016).

It has been further argued that guardianship has been misinterpreted and used to justify male superiority and mistreatment of the women in Islamic societies (Mir-Hosseini 2016). Indeed, gender ideologies attributing to traditional and socioeconomic values gained legal force in Saudi society by being associated with Islamic teaching. Women in Saudi Arabia did not have agency in terms of education, employment, and also accessing healthcare facilities for treatment without the consent of a male guardian.

By the year 2017, the government of the Kingdom of Saudi Arabia had reviewed civil and labour laws and regulations that affected the ability of women to travel, work and participate in the Saudi society. Vision 2030 was established to improve the status of the Kingdom of Saudi Arabia through multiple agendas recognising that a successful, modern nation must encourage and empower all members of society, including women (Embassy of the kingdom of Saudi Arabia in Washington D.C 2019). The status of women and their rights have improved and expanded since the announcement of the new agenda, and Saudi women are noted to be more engaged than ever in the society, government, and business. This has resulted in creating equal job opportunities for men and women in the Saudi workforce (Embassy of the kingdom of Saudi Arabia in Washington D.C 2019).

It has been reported that female education prior to the discovery of oil in Saudi Arabia was rejected by Saudi scholars and the community. Indeed, Prokop (2003) stated that at that point it was necessary to convince and assure the society and religious scholars that the purpose of educating a girl is to teach her Islamic teaching and to be a good mother in order to gain their approval. Thus, between the years 1960 and 2005, women's education was under the control of members of the conservative religious scholars who supervised educational curriculums (Hamdan 2005). However, the educational facilities and curriculums available for women were noticed to be different from those available for men. For example, gender differences and inequality were normalised in curriculum content at all school ages for boys and girls, particularly in resources relevant to Islamic teaching; and it was oriented towards preparing girls to be good wives and mothers. In addition, girls used to have special teaching about home management where they learned how to cook, sew, and clean. Conversely, boys had

physical education lessons which were not permitted for girls. This disparity has changed though because in 2005 women's education came under the administration of the Ministry of Education (MoE) which had previously controlled male education. Since then, women have been allowed to travel abroad to finish their studies in highdemand subjects. Saudi women were recently legally granted the right to make their own medical decisions in addition to education and employment (Muaygil 2018).

#### 2.3.2. The improvement in the status of Saudi women

Movements toward empowering the status of women in Saudi Arabia started in the era of King Abdullah from 2005 to 2015. Since 2015, and under the leadership of King Salman, the roles of women in society are being reformed towards becoming more independent in all aspects of life. Driving ban restrictions for women have been lifted and there are currently no strict dressing codes except for modesty in accordance with Islamic laws. Women now have various opportunities in education, employment, and participating in public sectors. Gender revolution in essence is one of the crucial agendas of vision 2030 (Vision 2030). Thus, instead of the previously imposed patriarchal system, increasing the participation of both genders equally in society has become important, in addition to respecting each gender and its contribution to society.

The traditional view of women's role has made Saudi women face a culturally unique situation with a shift from living under strict rules to participation in social formation through education and work. However, it is noted that women in some societies in Saudi Arabia are still expected to maintain these traditional roles despite the ongoing governmental attempts to empower women and improve their status. Moreover, the population of interest in this study are around the age of menopause, and they are from a generation that has gone through these foundational changes in the social status of women in Saudi Arabia. The response of this group of women to women empowerment agendas embraced by the Saudi Arabian government is not yet discovered; thus, it is unknown whether their lifeworld is affected by these continuous changes or if it continues to be governed by the traditional cultural system.

#### 2.3.3. Women's sex life in Saudi Arabia

Alomair et al. (2020) stated that sexual health in Saudi Arabia is determined by a complex relationship between four factors: personal, community related, cultural, and

religious factors in addition to existing policies and regulations. The statement of Alomair et al. (2020) supports the notion of Tobergte and Curtis (2013) which suggests that sexuality is socially constructed. The complex impact of cultural and religious factors on women has been affecting all areas of their lives, including their sexual relationships. However, as it was mentioned above, the Saudi culture is greatly informed by religion; hence, much of the discussion here will be presented from the Islamic religion point of view.

#### 2.3.3.1.Religion and Saudi women's sex life

Religion is understood to shape one's attitude towards sex, Yusof et al. (2010) have identified religion as a framework to guide sex life. According to Khoei et al. (2008), religion has been historically connected to three dimensions: sexuality, culture, and gender. Each religion or culture interprets and views sexuality differently. This notion is indeed relevant particularly when observing the sexual life of men and women in Islamic countries. The religion of Islam does play a critical role in shaping its followers lifestyle and education. There are certain acts that are accepted and legal in Islam but could be the complete opposite in western societies or different religions such as allowing men to seek up to four wives. There are acts that are illegal and forbidden by the religion of Islam such as extramarital sexual relationships and same-sex relationships. Recognising such differences and acknowledging the cultural sensitivity is fundamental when exploring the experience of a culturally sensitive condition similar to prolapse.

The sexual and reproductive experiences of Saudi Arabian women are reported to be influenced by many factors including the sociocultural norms in the country, the religious beliefs women hold, and gender related expectations (Alomair et al. 2021). This is not unique to Saudi women only, but broadly women from Islamic societies globally. As per Islamic laws, sexual relationships are only permitted between husband and wife. Extramarital sexual relationships and same-sex sexual relationships are prohibited by Islamic laws (Sanjakdar 2009). Marriage in Islam is viewed as the only legal method for sex. This demonstrates the great value placed on religion in Islamic societies that extends to matters related to health and sexuality.

#### 2.3.3.2. Sexual related knowledge among Saudi women

It has been stated that women in Islamic countries have limited access to formal sexual health knowledge or education compared to women in western societies (DeJong et al. 2005). Although this has been reported in 2005, there is no evidence suggesting that there has been a positive change in Islamic and Arab societies in terms of women's access to sexual health education resources. Hence, it is understood that women in Islamic societies including Saudi Arabia would have poor sexual health outcomes due to the apparent lack of knowledge in sexual health (Rahman 2018).

In Saudi Arabia, there are no current formal resources of knowledge on sexual health for both genders except in Islamic books in schools (Saudi Arabia ministry of education 2019). Moreover, sex is taught as a spousal right conditioned by marriage (Alomair et al. 2021). Some religious scholars see that sexual and reproductive health education for unmarried women is against Islamic religious beliefs since religious practices provide protection against sexually transmitted infections (Alomair et al. 2020).

Respectively, it has been reported that Saudi women have limited knowledge about their sexual health (Alquaiz et al. 2012; Gaferi et al. 2018). Additionally, women in Saudi Arabia are reported to have apparent misconceptions about sexual health due to the limitation in the right educational resources and their dependence on seeking health information from the internet or occasionally from their mothers or teachers (Gaferi et al. 2018). Nevertheless, seeking information about sex on the internet has been regarded to be forbidden by religious scholars on a questions and answers Islamic website unless it was for marital purposes (Islamweb 2004).

Evidence showed that prolapse has a significant impact on women's' sex life (Zielinski et al. 2012). Prolapse is urogynaecological condition but its link to the sexual activity of women makes it a health condition relevant to sexual health. Given the social norms regarding sexual health and sexual related knowledge in Arab and Islamic societies including Saudi Arabia, it is unknown whether Saudi women would have formal knowledge about prolapse as a health condition that they may or may not have around the age of menopause.

#### 2.4. The Healthcare System in Saudi Arabia

As discussed above, the Saudi society was reported to be traditional, isolated, and poor before the discovery of oil (Mohammed Albejaidi 2010). The healthcare services were largely based on traditional practices and medicines because there was no standardised healthcare system. The process of establishing official healthcare services started in 1926 when King Abdulaziz Al-Saud (1880-1953), issued a Decree establishing a 'Health Department' (Mufti 2000). Despite the fact that the country was still underdeveloped and poor, this step was perceived as a significant milestone and could be described as the beginning of the modernisation and the emergence of an evidencebased healthcare system (Mohammed Albejaidi 2010)

By 1954, the Ministry of Health (MoH) was established. Al-Faris et al. (1997) stated that this step was the complete transformation of Saudi Arabia's health sector. The Saudi healthcare system witnessed a complete transformation when the government was able to establish the necessary infrastructure of primary healthcare, hospitals, and research facilities.

Currently, the healthcare services in Saudi Arabia are provided through two main sectors: governmental and private sectors. The governmental sectors are broadly classified into three categories under four different ministries: the Ministry of Health (MoH), the Ministry of Military, the Ministry of Education (MoE), in addition to the Ministry of the Interior (MoI). The latter three agencies are independent of the MoH in that they have their own budgetary allocation. The MoH is responsible for the overall supervision of the healthcare facilities, both in the public and private sectors (MoH 2008). The MoH provides free healthcare services for the citizens of Saudi Arabia and pilgrims visiting the holy mosques for religious purposes (Saudi Arabian Unified National Platform 2020).

The MoH has more than 3300 primary healthcare centers across the country acting as gatekeepers for hospital referrals (Walston et al. 2008). The health services in Saudi Arabia under the MoH are based on three levels; primary, secondary and tertiary fields (Almalki et al. 2011). The primary level is provided by primary healthcare centers, which are the first point of contact in the healthcare service and provides basic preventive and curative care. Individuals who need a higher level of care and

interventions are referred to secondary care in public hospitals (Al Otaibi 2017). If the cases are complicated and need more complex care, they are referred to tertiary level care such as specialized hospitals (Al Otaibi 2017). It is observed that this system has led to longer waiting times for hospital care, overuse of the emergency departments and increased load on private healthcare services. As an example, the waiting time for surgeries in MoH hospitals ranges from several months to years. Thus, with increased demand on healthcare services in Saudi Arabia, private healthcare services are continuously growing, and patients can pay to receive fast and high-quality care. Private sectors can also be accessed by healthcare insurance, which is provided by most companies in Saudi Arabia for workers and their families.

Another route for accessing free healthcare services in Saudi Arabia is through The Ministry of Military hospitals which includes the Armed Force Hospitals (AFH) in addition to the Saudi Arabian National Guard Health Affairs (NGHA). The military hospitals offer medical and healthcare services, comparable with westernised standards, to members of the military and their families (Walston et al. 2008).

The MoE funds the university hospitals and teaching hospitals. These hospitals provide free medical and healthcare services to patients in addition to free practical training opportunities for medical and different healthcare students. Accessing university hospital for research is much easier than any other governmental hospitals under different ministries.

#### 2.4.1. Healthcare services for women

It has been stated that providing high quality healthcare services to women is one of the priorities of the government of Saudi Arabia (Almalki et al. 2011). Therefore, in each region of Saudi Arabia, there is a combined hospital specialised in maternity and childcare. Mother and childcare services are free of charge except at private healthcare facilities. These services include preventative healthcare, antenatal and postnatal care, and high-risk cases where pregnant women are transferred to a hospital specialising in obstetrics or gynaecology in case of emergency.

The United Nations (UN) (2010) estimated that the life expectancy of Saudi women increased to 74.7 years in 2009, which was perceived as a result of positive changes in women's status around that time. Indeed, evidence suggests that empowering women

educationally is accompanied by health empowerment as women benefit from available health services. This has led to improving general health in Saudi Arabia, a decline in the incidence of certain diseases and the total eradication of others (Al-Amoudi 2017).

The current ongoing changes in the Saudi society seem to be promising for women in several aspects including healthcare. Until recently, the healthcare services that were provided to women in Saudi Arabia have been greatly informed by law (Mobaraki and Soderfeldt 2010), and because of this, women's' admission to governmental hospitals was prevented unless under the consent of a male guardian. These regulations, however, were not applicable to all healthcare facilities or hospitals in Saudi Arabia but they did apply to the MoH, which as noted above has been the dominant healthcare provider in the Kingdom.

In addition to law, the culture of Saudi Arabia has been identified as an obstacle that can also make it difficult for some to seek health services, either during pregnancy or later (Mobaraki and Soderfeldt 2010). For cultural reasons, The physician's gender has also been reported to prevent women from receiving medical care as women do not prefer being seen by a male physician or at times not allowed so by their male guardian (Mobaraki and Soderfeldt 2010). Many women prefer to be seen by female physicians, which is sometimes difficult due to a shortage of female healthcare providers in some specialities.

#### 2.4.2. Physiotherapy practice in Saudi Arabia

Al Mohammedali et al. (2016) stated that the physiotherapy profession plays an integral part in the healthcare system; indeed, physiotherapy contributes to many medical specialties, such as musculoskeletal, neurology, and cardiopulmonary care and more. The Saudi Physical Therapy Association (SPTA) joined the World Confederation for Physical Therapy (WCPT) in 2003 which suggests that physiotherapy is perceived as a relatively new discipline in healthcare in Saudi Arabia. The standards of physiotherapy practice are not well defined in Saudi Arabia; however, physiotherapists follow the codes of conduct of regulatory and licensing authorities such as the Saudi Commission for Health Specialties (SCFHS).

In Saudi Arabia, physiotherapy services are offered across different healthcare settings including long-term care facilities, private clinics, home health care, and sports

rehabilitation centres. Physiotherapy is provided at secondary and tertiary level hospitals but is not available at primary healthcare centres (Al-Abbad and Madi 2020a). It has been suggested though to integrate physiotherapy services to be provided at primary healthcare facilities. This is because primary healthcare services are thought to provide health promotion and curative and rehabilitative care in accordance with local population health needs (Jahan and Al-Saigul 2017). Usually, patients need referrals from physicians to access physiotherapy treatment in Saudi Arabia, or alternatively, they can refer themselves to private practices (Al-Abbad and Al-Haidary 2016). Physiotherapists are expected to assess and treat; yet, they are not involved in screening patients, and they do not take part in the referral decisions in Saudi Arabia (Al-Imam and Al-Sobayel 2014). It is often the case that physiotherapists are not autonomous in their decision making, and the treatment plan is decided by physicians, thereby limiting the physiotherapists' scope of practice. General practitioner (GP) surgeries in the United Kingdom (UK) are the equivalent to primary healthcare centres in Saudi Arabia (PHC). GPs act as gate keepers to the National Health Service (NHS), with specialised healthcare predominantly accessed via GP referral. Direct patient access to physiotherapy through NHS self-referral schemes is permitted in the UK, while in Saudi Arabia patients can only self-refer to physiotherapy at private clinics. Studies have shown that first point of contact physiotherapy is acceptable to patients and GPs in the UK, and physiotherapists were able to manage most patients (Martini and Kelly 2017). Moreover, staff and patients reported satisfaction with the services (Downie et al. 2019).

In line with the Saudi 2030 Vision, the MOH has recently introduced a new model of PHC delivery to ensure early access to health care services to individuals in their community, and to relieve the workload on secondary and tertiary level care fields (Al-Abbad and Madi 2020b). This is aimed at improving the quality and coordination of health care services. So far, some PHC centres were designated to provide oral health care, emergency services, nutrition clinics, counselling and antismoking clinics, and other specific medical consultation services in addition to standard general medical services. However, physiotherapy is not currently a part of these PHC services. Physiotherapy service in governmental sectors is only available at secondary and tertiary level hospitals which leads to difficulty and delay in patients' access to the service.

Moffatt et al. (2018) suggested that the successful implementation of self-referral and direct access to physiotherapy requires a number of cultural shifts both from a patient and a professional perspective. From a patient perspective, there was evidence to suggest an intransigent patient believes that the GP was the default first point of contact practitioner in the UK (Goodwin et al. 2020). In Saudi Arabia, however, physicians are the dominant decision-makers, and they are the gatekeepers for accessing physiotherapy in Saudi Arabia; with the physicians' views of physiotherapy potentially affecting the treatment received by the patient (Al-Abbad and Madi 2020b)

One study showed that physicians and nurses in Saudi Arabia would welcome more information about the role of physiotherapy within respiratory care, as the majority of respondents did not believe they had received enough information regarding the role of physiotherapy during their formal training (Al Mohammedali et al. 2016). Nearly half of the respondents did not view physiotherapists as important members of the intensive care unit (ICU) team and reported not knowing what the role of the physiotherapist was in this setting. A study by Al-Muqiren et al. (2017) reported that in Saudi Arabia, 58% of physicians have a negative perception of physiotherapy as a profession, which results in limited utilisation of physiotherapy services for all conditions.

#### 2.4.3. The scope of women's health research in Saudi Arabia

The existing knowledge regarding the prevalence, risk factors, and consequences of living with pelvic organ prolapse in Saudi Arabia is scant. Pelvic organ prolapse is a subject of interest for researchers from different parts of the world while in Saudi Arabia, there are a very limited number of studies, and there are no published figures or prevalence rates data. Following extensive database searching on pelvic organ prolapse in Saudi Arabia, no studies were found. When using the key terms: "pelvic organ prolapse" and "Saudi" in the CINAHL database for example, only two studies were identified, both of which were irrelevant. Searching for key terms "Saudi" and "urinary incontinence", using the CINAHL, AMED, and Medline databases a total of six relevant studies were identified, with two studies reporting the prevalence of incontinence in Saudi Arabia. This could suggest that the issue of urinary incontinence not being such a hidden issue due to its impact on hygiene which is significant in religion of Islam. Praying requires a certain set of steps of cleanness known as "wodo'o". If one

leaks urine or passes stool, she or he must begin to perform wodo'o again so that they are allowed to pray, otherwise their prayer will not be accepted. As religion plays a critical role in Saudi Arabia, men and women experiencing urinary incontinence might reach out for help because praying is disturbed.

When searching for the key words "women" and "Saudi Arabia OR Saudi" in the data bases indicated above, a total of 38 studies were retrieved. The topics of the studies ranged between health and social studies. None of the studies was however relevant to prolapse. This perhaps informs the limitation broadly in women's health research in Saudi Arabia specifically women's health physiotherapy.

#### 2.5. Chapter summary

This chapter provided a contextual description of the kingdom of Saudi Arabia. It demonstrated the role of religion in the formation of culture and traditions in the kingdom. The religious roots of Islam in the Arabian Peninsula can be traced up to 1400 years ago, this resulted in making the line between religion and culture in Saudi Arabia to be ambiguous. Respectively, the religious and traditional system in Saudi Arabia has been governing the lives of women. This chapter provided an overview of the lives of women in Saudi Arabia and the rules that have been controlling their roles in the society whilst highlighting the ongoing changes in the kingdom. The healthcare system in Saudi Arabia with a focus on physiotherapy particularly women's health physiotherapy has also been discussed here and it demonstrated the potential issues of womens' health physiotherapy service provision for women with prolapse.

The next chapter moves beyond describing to context to critically evaluating the current literature about the experience of prolapse.

# 3. Chapter Three: Scoping Review of The Literature

# **3.1.Introduction**

This chapter examines and reviews the relevant available evidence and aims to identify whether there is a gap in the literature and what the missing understanding is in terms of the experience of prolapse. Literature related to the experience of women with prolapse is reviewed in this chapter. POP includes a wide range of symptoms; thus, the implication of living with this condition and the bothersome associated with experiencing the symptoms, as reported in current literature, will be presented here. The findings of these studies will then be contextualised to my study settings, this step will help in understanding whether the experience of prolapse reported in the literature is representable of the experience of Saudi women or not, which will further justify the study. Moreover, it will aid in identifying the suitable method to address the experience of POP in Saudi Arabia.

When conducting the literature search, the aim at first was to identify research conducted in Arab and Islamic countries thereby sharing a similar background with Saudi Arabia and exploring the experience of prolapse in conservative societies. However, following the initial search in different databases, studies conducted in Arab and Islamic countries were limited and it was deemed appropriate to expand the inclusion to international studies with a variety of cultural backgrounds. This inclusion might help in gaining an understanding of the role of different cultures in shaping the experience of the condition. The studies identified were diverse in their aims and methodologies, therefore it was decided to conduct a scoping review in order to identify the gap in the knowledge, scope the existing body of literature, clarify concepts and to investigate the research conducted (Munn et al. 2018). Scoping review generally provides an overview of a broad topic, considering the proposed research question, studies explored the experience of women with prolapse covered different types and stages of prolapse and in some studies, there was not much information given on the prolapsed organ, in addition the studies designs, and methodologies were also inconsistent; thus, using scoping review framework seemed suitable in this review.

The review was guided by the following research questions:

- What is the experience of perimenopausal and menopausal women with pelvic organ prolapse?
- How does pelvic organ prolapse affect the lives of women in different social and cultural backgrounds?
- What are the roles that are culturally specific to women and disturbed by the symptoms of pelvic organ prolapse?
- How does the cultural background of women influence their experience of pelvic organ prolapse?

# **3.2.Search strategy**

For this literature review, an electronic search was conducted between October 2018 and January 2019, prior to the development and submission of the research proposal. The search was further repeated between March and April 2022. The purpose of the scoping review was to explore the lived experience of women with pelvic organ prolapse. It presents a global view due to the lack of specific literature informing the Arab and Islamic perspectives. The following table (Table 1) demonstrates the keywords and their synonyms that were used to facilitate the search:

Pelvic organ prolapse	'POP' OR 'Prolapse' OR 'vaginal prolapse' OR 'uterine prolapse'
Lived experience	'Experience' OR 'living with'
Quality of life	'QoL'
Body image	'Sexual body image'
Healthcare seeking behaviour	'HCSB' OR 'coping'

Search for literature was conducted on the following databases: CINAHL, AMED, MEDLINE, Web of Science, Cochrane library and SIGLE. In addition, references were identified manually by searching the references of the retrieved papers for relevant papers (e.g., by tracing citations through the reference lists and key journals), besides performing an extensive search of 'grey' literature, such as dissertations and theses. To ensure transparency, while searching for the related literature, the available literature about the experience of women with prolapse was explored in Google Scholar to gain a general view of what is known about the topic. This was followed by reviewing the articles by title and abstract to identify the key journals, and to identify further keywords that were used in those references.

#### 3.3.Study selection criteria

#### 3.3.1. Participants

As the aim of this study is to explore the lived experience of women with prolapse around the age of menopause, studies including women with an age ranging from 40 to 60 and older were included in this review. Studies that included younger women with symptomatic prolapse were excluded. This is first attributed to the population of interest for the proposed study and to ensure homogeneity and rigour. Secondly, it is indicated that prolapse typically and symptomatically affects women around the age of menopause with a prevalence of 30-50% (Durnea et al. 2014). The symptoms of uterine prolapse usually appear around the age of menopause, but it can also be asymptomatically present postnatally because traumatic birth events are a risk factor for prolapse (Schaffer et al. 2005). Around the age of menopause, it has been reported that the level of oestrogen production starts to decrease due to a ceasing of ovulation (Kinman et al. 2017). Evidence suggests that the level of oestrogen is correlated with women's pelvic health; thus, the decrease of oestrogen has been linked to vaginal dryness and subsequent sexual dysfunction for some women (Kinman et al. 2017). The hormonal and physiological implications of menopause often lead to vaginal atrophy, and in case asymptomatic prolapse was present prior to the menopause, the symptoms start presenting following the menopause and women start noticing it. This review aims to explore the experience of prolapse, therefore it was important to include studies that include women with experience of symptomatic prolapse.

## **3.3.2.** Concept

Studies that recruited women who underwent corrective surgeries were excluded from this review because the views of this group of women may differ from those who did not undergo any surgical interventions. Prolapse has been reported as a "covert" condition (Pakbaz et al. 2010), and it is possible that women tend to delay seeking healthcare, therefore studies that included participants without a medical diagnosis were included in this review in addition to women who were medically diagnosed with prolapse. This has aided in identifying the potential barriers and facilitators to seeking healthcare and establish an understanding of how women self-manage their condition.

In terms of the methodologies, studies that incorporated quantitative, qualitative, and mixed methodology designs were included in the review. This is due to the structure of the scoping review, unlike systematic review of literature, scoping review offers flexibility in including diverse relevant literature (Munn et al. 2018). Grey unpublished literature was also included in this review. These steps supported the greater breadth of the scoping review. As scoping reviews are designed to provide an overall view of the literature regardless of the quality, the methodological quality of the studies were not considered during the selection process; however, the methodological quality of each study was analysed, and the strengths and limitations were discussed in the analysis of the papers.

### 3.3.3. Context

This review includes studies conducted in different geographical locations. This is because of the heterogeneity in the contextual backgrounds of the identified studies. In addition, in some cultures, particularly Arab and Islamic societies, prolapse could be considered a sensitive topic due to its impact on women's sexual health (Athanasiou et al. 2012). Therefore, one of the objectives of this review was to investigate how culture may influence the perception and experience of prolapse. The professional background of the authors was not considered in this review, with studies conducted by nurses, midwives, physicians, and physiotherapists all were included, notably these are all healthcare professionals

#### **3.4.**Quality assessment of the studies

Twenty-seven articles met the inclusion criteria. Abstracts for each of these articles were considered for relevance to the research aims and objectives. The core studies that addressed the review questions (outlined above) were included and are presented in a table in the appendices (appendix L). The main purpose of this table is to summarise the content of each core paper and to identify strengths, limitations, and to compare similarities and differences between papers, thereby identifying the emergent themes.

The Critical Appraisal Skill Programme (CASP 2013) tool was selected to review the research papers in this scoping review. It is one of the most widely used set of critical appraisal tools (Aveyard 2018) which provides a clear and systematic approach for examining studies (Buchholz et al 2013). CASP has designed different tools to evaluate different types of research including randomised controlled trials, systematic reviews, cohort studies and case-control studies. (Buchholz et al. 2013) The aim of the CASP tools is to enable students and clinicians to develop the skill of finding and making sense of research and assist them to transfer knowledge into practice (Hopp and Rittenmeyer 2015).

#### **3.5.Studies characteristics**

A total of 27 relevant studies were identified following the search. The studies were diverse in terms of aims, methodological approaches used and demographics. Some studies aimed to explore specific issues in women with prolapse such as body image perception and sexual function, knowledge about prolapse, or women's healthcare seeking behaviour after developing the condition. Other studies aimed to obtain a wider perspective and explored the overall experience of living with pelvic organ prolapse or assess the quality of life after developing the condition.

Qualitative studies have used ethnography design, thematic analysis, grounded theory, and phenomenology. A wide range of instruments has been used in quantitative designs such as the Prolapse quality of life questionnaire, Pelvic organ prolapse/urinary incontinence sexual questionnaire, and Prolapse and Incontinence Knowledge Questionnaire. Some studies used self-developed questionnaires, but the validity and reliability of these questionnaires were unclear.

The majority of studies were conducted in westernised societies such as the USA, UK, Netherlands, Sweden, Greece, and Mexico which may suggest more liberal cultural contexts. Only four studies were conducted in Arab or Islamic societies such as Pakistan, Iran, Turkey, and United Arab Emirates. Four studies were conducted in countries that have mixed cultural and religious backgrounds such as Ethiopia, Nepal, and South Africa. The following section presents the relevant studies according to their central aim.

## 3.5.1. The lived experience of pelvic organ prolapse

The lived experience of pelvic organ prolapse was one of the aims that have been focused on in the existing literature. The studies that looked at the experience of prolapse incorporated different qualitative research designs and provided a rich description of the experience. Generally, these studies highlighted the impact of culture on shaping the experience of prolapse. However, none of these studies was conducted to explore the experience of women from Arab or Islamic societies. The findings of the studies that looked at the experience of prolapse might not be transferrable to another context due to the adopted research designs. In order to further identify and demonstrate the gap in the literature, the contextual background of these studies is considered and then compared to what is known about the culture of Saudi Arabia. Identifying the similarities and differences between the Saudi culture and the cultural backgrounds of studies that explored the experience of prolapse will clarify why the findings of these studies may not be representable of the experience of prolapse in Saudi Arabia. Indeed, this will help in exploring how the experiences of women from different backgrounds may or may not relate to Saudi women given what is known about the Saudi Arabian culture.

The most recent study published was the study of Gjerde (2017) which explored the experience of 32 Ethiopian women aged between 24-70 years with grade two prolapse or more. Data were collected using in-depth interviews and findings reported five themes: conceptualizing the condition, daily life challenges, sexual implication, managing the condition, and disclosure. The perception of POP among Ethiopian women was that the condition was shameful and disgusting and women did not want to disclose this information for the fear of being discriminated against. Women considered childbirth to be the cause of prolapse in addition to the lack of rest during or after

pregnancy. Some of the daily life challenges reported by women in the study were bound to the context. For example, women indicated problems with water fetching, which is relevant to the water crisis in Ethiopia, placing a further burden on women and adding to their responsibilities. Most study participants reported remaining sexually active despite the presence of prolapse symptoms because "this is marriage", but that they would sometimes sleep alone and lie to their spouse to avoid intercourse. Some women reported that they were separated from their spouses because of prolapse. In essence, it is reported that Ethiopia is a male dominant society which puts women in lower status position than men (Haregewoin and Emebet 2003), this potentially explains Ethiopian women's attitude towards intercourse while experiencing POP symptoms. Women felt there is no solution, they were worried and experiencing pain but continued living their lives doing their daily work but took rest between activities, sat on folded clothes to avoid pain, pushed their uterus in when urinating, and rubbed with oil to moisten. The author concluded that the reported low socio-economic profile of women in Ethiopia shaped their experience of POP (Lailulo et al. 2015). In addition, the societal structure in Ethiopia that resulted in a lack of female autonomy and empowerment could explain their responses towards their illness (Ethiopian Society of Population Studies 2008).

The qualitative method used in this study provided a deep insight into the lived experience of POP and highlighted some specific cultural issues surrounding the experience. Comparing the context of this study to Saudi Arabia, it is noted that there is a wide range of differences but there are also a few similarities in terms of the cultural issues reported in the findings that may be explained by the shared religion of Islam between two countries. This was particularly noted in issues reported related to the sexual implication of POP and women's responses to having an active sex life despite how tired they felt because of prolapse symptoms. The lives of women in Saudi Arabia have also been governed by a patriarchal system that is less favourable to women. However, as presented in chapter (2), the social norms in Saudi Arabia are changing and it is unknown whether these issues persist and how these changes might inform womens' realities in Saudi Arabia, and their experience of POP.

The study of Gjerde (2017) reported that women perceived early marriage to be a risk factor for prolapse. Early marriage or child marriage is indeed reported to be common

in Ethiopia (Lailulo et al. 2015). The women's realities in Ethiopia have shaped their understanding of the condition. They were involved in such practices because it was historically a part of their culture, and it is argued that Saudi Arabia has also been known to have a high rate of early marriage as compared to other Arab countries (Al-Khraif et al. 2020). Prior to 2019, there was no minimum legal age for marriage in Saudi Arabia and many girls were married as soon as they had their first menstrual period (Shawky and Milaat 2000). Shawky and Milaat (2000) also reported that the rate of early teenage marriage was found to be approximately 27.2% in the city of Jeddah. It is believed that early marriage for girls in particular in Arab and Islamic societies is congruent with culture, traditional values, virginity and family honour being the main reasons for this practice. In 1992, it was reported that a total of 6.6% of the Saudi population below 20 years were married: 0.7% among males and 12.5% among females (Salam 2013), suggesting a higher gap in age at the time of marriage between males and females. Mean age at the time of first marriage has been significantly raised, since 2019 due to a notable increase in female education (Al-Khraif et al. 2020). This might suggest increased awareness within the population, yet it is worth exploring if normalising early marriage many years ago in Saudi Arabia has resulted in shaping the understanding of the current generation of women of POP.

Another study that explored the lived experience of POP was the study of Shrestha et al. (2014). Sixteen women with prolapse grades three or four were interviewed, no information was provided about the age of the study participants. This study also explored women's healthcare seeking behaviour through quantitative methods. Women in this study reported great disturbance due to prolapse symptoms including sexual dysfunction. Spousal responses to the problem included harassment and threats to remarry or separate. Women reported facing domestic violence and some were excluded from social activities. In terms of self-perceived reasons for prolapse, women considered repeated pregnancies and heavy work during the postnatal period to be major causes. Similar to the study of Gjerde (2017), the findings of this study demonstrated that women's experience of POP was impacted by their cultural background and understanding. Some of the issues reported in terms of spousal behaviour may be relevant to women in Saudi Arabia. The social norms in Nepal are informed by Hindu traditions that is also known to be a patriarchal society (Hamal Gurung 2014). Moreover, polygamous marriages are allowed by religion in Nepal and

Saudi Arabia which may give men more power over women as Hamal Gurung (2014) reported in relation to abuse of social power, threats of separation and remarrying. Polygamous marriages are indeed legal in Saudi Arabia given its accordance with Islamic rules and men under the law of Islam are allowed to seek up to four wives. Unofficial data give contradictory rates of polygamous marriages in Saudi Arabia. Throughout the last decades, the role of a good wife in Islamic societies has been defined in terms of attending to the needs of the husband, and as allowed by religion, a man may seek another wife if his first wife fails to perform what was expected from her (Alturki 1986). Moreover, reluctance to meet a husband's sexual desire further provides a husband with a socially acceptable excuse to look for another wife. Some argue that polygamous marriages are consistent with gender-related differences between men and women in terms of their needs that includes social, financial, and sexual needs (Al-Krenawi 1999). This issue has remained controversial in the wider context because it represents an asymmetry of power between men and women that appear similarly linked to male domination. In some Arab and Islamic communities, multiple wives are considered a measure of a man's wealth or status, similarly, men may seek out multiple wives to increase their wealth and number of offspring, using these large family networks to forge familial alliances (Nanda 2018), and even because of a wife's illness and inability to perform what is expected from her as a wife such doing house duties and attaining to husband's intimate needs (Almegewly 2017). Nevertheless, evidence has shown that Saudi women in polygamous marriages report low self-esteem and depression (Al-Krenawi 1999).

High parity was perceived as a risk factor for prolapse in the study of Shrestha et al. (2014). The world bank (2022) data show that the fertility rate in Nepal has decreased in the last 50 years from 5.9 to 1.8 in 2019. Data shows that fertility rates in Saudi Arabia were steady from the 1960s to the 1980s with an average of 7.2 births per woman and gradually decreased to 2.2 births per woman in 2019, which is higher than the rates in Nepal (The World Bank 2022). Many years ago in Saudi Arabia, the declaration of any form of birth control, under any circumstance, was perceived as contrary to the faith of Islam. In addition, a lack of methods of regulating fertility has led to high birth rates resulting in continued population growth in Saudi Arabia. One study demonstrated that married women in Saudi Arabia gave birth to more than nine children (Salam 2013). Moreover, such high parity was reported for women aged 45 to 64,

demonstrating that women reach high levels of fertility by the end of their reproductive span (Salam 2013). This could be a result of women's awareness that they are reaching the age of menopause where they are no longer fertile and perhaps reflects attempts to ensure they have large families. In many Arab societies, menopause is defined as the "desperate age" which reflects how their inability to conceive means that society considers them to be in dire need or despair. Nevertheless, frequent childbearing is reported to negatively affect Saudi women's health in general. One study showed that iron deficiency (Anaemia) was prevalent among Saudi women and identified a link between Anaemia and a high rate of pregnancy and poor birth spacing (Mahfouz et al. 1994).

Roets (2007) conducted a phenomenological study using in-depth interviews with 19 women from South Africa with an age range from 48-77. Eight women had first degree prolapse, eight had second degree, and three had third degree prolapse. Women reported that they experienced shame and anxiety, but women related these emotional symptoms to urinary incontinence (UI). Women with first and second degree prolapse reported disturbed self-esteem and limited engagement in social activities as a result specifically of UI. UI resulting from POP was perceived as more problematic than the prolapse itself. Surprisingly, prolapse did not affect social interactions, activities or selfesteem of the women with third degree prolapse. Generally, it was reported that the social behaviours of women were not impacted to the same degree. Moreover, some of the study participants wanted to seek professional support but were too shy to do so. Others have accepted the condition and no longer complained about it. The age of the participants in each prolapse group was not specifically mentioned which might have been helpful to contextualise their responses, but overall, this study indicated lack of knowledge or education about prolapse among women in South Africa. Evidence suggests that discussing sexual health issues is taboo in South Africa which might explain the differences in views generated from the interviews (Moult 2013). Similarly in Saudi Arabia and broadly Islamic societies, discussing sexual and reproductive health is regarded as taboo and improper (Kingori et al. 2018). Few studies demonstrated that Muslim women are often hesitant to discuss such topics even with close family members (Meldrum et al. 2015). This may have resulted in prolapse being an under-reported health problem, in addition, it may also cause the experience of prolapse in Saudi to be private. Al-Zahrani (2011) reported that Saudi women delay

seeking healthcare support for sexual related health problems due to the impact of social norms around sexuality in Saudi Arabia. Respectively, sexual healthcare services provided to women are reported to be limited in Saudi Arabia (Al-Zahrani 2011). Literature suggests that culture is one of the key barriers contributing to the suppression of discussing sexual and reproductive health issues amongst Muslim women (Abedian and Shahhosseini 2014; Mosavi et al. 2014; Behboodi Moghadam et al. 2015).

Lack of knowledge about prolapse was also reported among American and Spanish women in the study of Dunivan et al. (2014) that explored the experience of POP through focus group interviews. Women indicated feelings of shame regarding their condition, difficulty in talking with others, fear related to their symptoms, and emotional stress from coping with POP. The authors suggested that in addition to culture, the nature of the problem makes it difficult to be discussed even in westernised societies. What was unique about this study is that women reported sense of shame and difficulty talking about prolapse yet they engaged in discussions during the interview while surrounded by other women. This tells something about the contextual background of the study that was conducted in the USA. Women had such sensitive concerns but were not hesitant to speak about them in front of other women. This might be a result of peer pressure or support, but it also might be relevant to the fact that women were from westernised societies where sexual health issues are not as taboo as in Saudi Arabia. It can be argued that focus group interviews might not be suitable to address the experience of Saudi women as their responses cannot be predicted due to the current lack of literature and thereby understanding.

### **3.5.2.** Quality of life

Six studies used three different quality of life (QoL) assessment tools to measure the QoL of women with prolapse. These studies aimed to generate a holistic view of the experience of prolapse using different quantitative methods, but it resulted in providing a limited and reductionist perspective of the experience. There was inconsistency reported in the studies processes and findings. In addition, there was a lack of parity regarding the QoL questionnaire that would sufficiently capture the implication of prolapse on women's QoL. For example, Brandt and van Vuuren (2019), Srikrishna et al. (2008), and Digesu et al. (2005) have used the Prolapse Quality of Life questionnaire (P-QoL). P-QoL has been described to be a simple, reliable and easily comprehensible

instrument to assess the severity of POP symptoms and its impact on women's QoL. It was developed by Digesu et al. (2005) who also administred it to 355 participants in the UK, 233 women had prolapse (mean age 57 years), and 122 were controls (mean age 48 years). Findings demonstrated that P-QoL scores were significantly higher in women with prolapse. This cannot be considered a significant finding because the scores of the questionnaire were compared to women with no prolapse that were in the control group, which is understandable as this study was the first to assess the validity of the questionnaire. However, the study of Srikrishna et al. (2008) showed that administering the P-QoL questionnaire to 43 women with mean age of 56 also in the UK was not representative of the actual experience of prolapse. This was a mixed methods study, and the statistical analysis demonstrated that women were not significantly bothered by the symptoms of prolapse which was contrary to the findings of the qualitative data. The questionnaire was reflective of emotions and energy, symptoms, and psychological factors of women but general health judgement, role limitation, physical and social activity and sexual function were not sufficiently reflected in the P-QoL questionnaire. Srikrishna et al. (2008) concluded that designing subjective patient-oriented goals might be more appropriate for women with POP rather than objective goals that are often represented in the QoL questionnaires. The P-QoL questionnaire was designed and first administered to women in the UK (Digesu et al. 2005), but when used again with a similar population, it failed to reflect the experience of the same women who provided an additional verbal discourse. Contrary findings were reported by Brandt and van Vuuren (2019) when P-QoL was administered to 100 South African women, mean age of 59 years old as the symptoms reported by women correlated with P-QoL assessment.

Transferring P-QoL to be used in other non-western settings such as Saudi Arabia would require translating the contents and given the current lack of evidence to support its use this would be difficult to justify. A Turkish version of P-QoL was translated and administered to 179 Turkish women (Şahin and Vural 2015). The study indicated that there was no impact on QoL; indeed, findings showed that QoL was only impacted when there was an increased degree of prolapse of "grade three or more". Şahin and Vural (2015) acknowledged that there were a number of methodological limitations in this study and therefore and the reliability of P-QoL cannot be judged by their findings. Given the findings of this study and the others using P-QoL to measure the impact of

prolapse, there is a doubt about the use of P-QoL because of the contradictory findings. Hence, it can be argued that it might not robustly address the experience of women and the implication of POP on their QoL or provide a deep enough insight into the experience of this little understood phenomena

The Health Related Quality of Life tool (HRQoL) was used to assess the QoL of women with POP but only in the study of Sami et al. (2015). Here, the impact of multiple gynaecological morbidities on the QoL of women from Pakistan was assessed. This study demonstrated that vaginal prolapse has the most significant effect on the HRQoL of affected women compared to other gynaecological issues. HRQoL is not specific to prolapse but it encompasses a wide range of human experiences, including functioning and subjective responses to illness. Because this was the only study that used HRQoL with women with prolapse, it can be argued that there is a limitation in the literature supporting the use of this tool with this population and further research is needed to support its use.

Another tool used to measure the QoL of women with prolapse was the QoL scale. Jelovsek and Barber (2006) used the QoL scale to assess the quality of life in women diagnosed with prolapse. The scores of 47 women with third and fourth degree prolapse were compared to 51 women with no prolapse. Findings indicated that the QoL of women with prolapse is significantly disturbed by the illness. Although the reliability and the validity of the QoL scale have been established in previous literature, this was the first study to administrate this questionnaire to women with prolapse. Despite the significant findings, it is unknown if these tools are representative of QoL of women of different cultural backgrounds such as Saudi Arabia.

## **3.5.3.** The sexual implication of pelvic organ prolapse

The sexual implication of prolapse is one of the issues that has been separately explored in literature. Nine studies were focused on exploring the impact of POP on the sexual body image and sexual function of women. Different methodologies have been adopted in these studies but overall, it is reported that prolapse greatly disturbs body image and sexual function. Studies that used quantitative methodologies identified the sexual implication of POP using different scales. Athanasiou et al. (2012) investigated the sexual health of Greek women with prolapse by using the Sexual Dysfunction Questionnaire (DYSQ). Sixty nine women with symptomatic prolapse and 61 women with no prolapse were included in this study. Women in this study were equally sexually active; nevertheless, women with prolapse had less desire and satisfaction and 49% were able to achieve orgasm. The study also indicated that the degree of prolapse does not correlate with sexual dysfunction because all degrees of prolapse were included. No statistical difference between the severity of prolapse and sexual dysfunction was detected. This particular finding may further provide an indication of the need to subjectively approach women when exploring the impact of POP on their sexual lives. This is because failure to detect significant differences would suggest that the experience is personal and individually experienced. Moreover, the DYSQ tool is specially designed to meet the study requirements of women with a Southern European cultural background which may not be transferrable to another context.

Another tool used to evaluate sexual function in women with POP is the Pelvic Organ Prolapse/Urinary Incontinence Sexual Questionnaire (PISQ). Rogers et al. (2001) explored the impact of pelvic organ prolapse and urinary incontinence on the sexual function of 83 women aged  $50\pm12$ . The findings of this study indicated that the sexual function of women with POP and UI was significantly affected compared to healthy women. This was not a surprising finding given the link of POP and UI to sexual dysfunction reported more generally in the literature. This tool however failed to identify the extent of dysfunction. Moreover, the age of participants in the control group was  $39\pm1$  and was significantly different from the study group which potentially affects the reliability of the findings.

In one study, Barber et al. (2002) developed a condition-specific sexual function questionnaire to assess sexual function in women with POP and UI. The findings of this study reported prolapse is more likely than UI to result in sexual inactivity and to be perceived to be affecting sexual relations. However, the reliability, validity, and internal consistency of sexual function questionnaires are unknown. Thus, it cannot be yet used to assess the sexual function of Saudi women with POP.

Female Genital Self-image Scale (FGSIS) (Herbenick et al. 2011), Female Sexual Function Index (FSFI) (Rosen and Brown 2000), and Body-Esteem Scale (Franzoi & Shields, 1984) have been used in a study by Zielinski et al. (2012) to understand how

prolapse influences genital body image and how genital body image influences womens' sexual health. The study included 13 women with prolapse, 24 women who had surgical reconstruction, and 37 controls. Despite the reliability of the tools used, the findings reported no significant difference across the groups, and this has been attributed to the small sample size. No other studies have used the same tools to explore the same outcomes in women with prolapse; hence, it cannot be concluded if these three tools are reliable when used with women with POP.

Pelvic Organ Prolapse/Urinary Inconvenience Sexual Questionnaire-12 (PISQ-12) was also one of the tools used to investigate the effect of prolapse on the sexual function of women. In the study of Özengin et al. (2017) questionnaires were administered to 132 women with prolapse and 36 controls. Again, no statistically significant difference was detected despite the proven reliability and validity of the used tool. This could be explained by the severity of prolapse in the study group which might also be a factor as to why a significant difference was not detected. Indeed, the women in the control group had asymptomatic grade one prolapse while some of the participants in the study group had 2nd degree prolapse, and the difference in symptoms between the first and the second degree prolapses may not be sufficiently different to observe any changes. This study was conducted in Turkey which is a country with Islamic background therefore it might be that women were hesitant to answer the questions related to sexual health due to cultural and religious barriers.

It can be argued from the studies above that there is a clear limitation in evidence in terms of the quantitative tools used to explore the sexual implication of POP on women. However, literature exploring the same outcome using qualitative methods has sufficiently reported the experience, and the studies incorporated minimal methodological limitations compared to quantitative studies. The findings of the qualitative studies however cannot be generalised to women in Saudi Arabia as studies were conducted in different contexts and the nature of qualitative research itself. For example, the study of Hadizadeh-Talasaz et al. (2019) investigated the sexual experiences of Iranian women with POP. Conducting in-depth interviews with 20 Iranian women aged between 44 and 54 years revealed that women did experience sexual discomfort due to prolapse. Women also reported having damaged body image of their genitals, with words such as "ugly," "smelly," "not normal," "dirty," and

"loose" used to describe the changes in their body after having prolapse. The women reported that they eventually started to feel less feminine due to these changes. Women also reported developing a range of negative emotional responses in their everyday life including depression, fear, anxiety, embarrassment, and anger as a result of the condition. Women shared their husbands' responses to prolapse and its implication on their sexual functioning which ranged from being indifferent to supportive. It was concluded from this study that the sexual implications of prolapse were more disturbing to women themselves than their spouses. This was a surprising finding because Iran is reported to be a male dominant society where the roles of men and women are predetermined by the religion and society (Ghaffari 2020). Historically, Saudi Arabia and Iran share similar religious roots. As it has been proposed in chapter (2), in Saudi Arabia, religion is a way of lifestyle. Similarly in Iran, Islam is practised by the majority of Iranians and governs their personal, political, economic and legal lives (NAFISI 2007). In Saudi Arabia, however, sex is taught as a spousal right conditioned by marriage (Alomair et al. 2021), this might not be the case in Iran. This is because evidence suggests that Iranian women are aware of their sexual health and needs (Merghati Khoei et al. 2015). It can be argued that different findings will be reported in terms of the sexual experience of women with POP because the sexual and reproductive experiences of Saudi Arabian women are influenced by many factors including sociocultural norms in the country, the religious beliefs women hold, and gender-related expectations (Alomair et al. 2021).

A qualitative study by Roos et al. (2014) utilised semi-structured interviews with 36 women in the Netherlands who planned to undergo surgery. Among them 17 women had prolapse, 8 had urinary incontinence, and 11 had prolapse and incontinence. Their ages ranged from 31 to 64. Women with prolapse reported a lack of sexual desire, reduced motivation, and fear of pain and discomfort. Women also reported difficulties with penetration and insecurity and were afraid that intercourse will cause further damage. The overall experience of sex was found to be unsatisfactory for women with prolapse due to disturbed sensation. Difficulty in achieving orgasm was also reported by women with prolapse due to reduced sensation. Dyspareunia was also reported by women with prolapse which made them avoid some positions during intercourse. This study also looked at the body image perception of women, being "Ugly, not normal, big, loose, old" was reported by women with prolapse. Moreover, women felt

embarrassed, depressed, and experienced the sense of low confidence, unattractiveness, and were concerned about their partners' experience. It was also noted that the sexual health of women did not correlate with the degree of prolapse. This further highlight that using quantitative methods might not detect significant findings or insights.

Zielinski and Miller (2009) aimed to understand the sexual experience of women with prolapse through semi-structured interviews with 13 women. Among these women, only eight were sexually active. Findings of this study indicated that UI rather than prolapse affected body image and sexuality for sexually inactive women. In addition, prolapse appeared to cause sexually active women to experience discomfort during intercourse and some women were concerned with partners' response. It was also reported that prolapse changes how women felt about their femininity. This study provides an important finding in terms of the perceptions of women that are sexually inactive about the sexual implication of prolapse. Because of the reported implication of POP on sexual function, it is important to understand the sexual experience of Saudi women with POP. However, identifying sexual activity as an inclusion criteria might not be respectful of the context of Saudi Arabia. From a cultural perspective, marriage in Islamic societies including Saudi Arabia is viewed as the only legal method for sex. Therefore, exploring the experiences of married women might provide an understanding of their sexual experiences. In essence, it is noted that the majority of sexual health related studies broadly in Muslim societies are focused on exploring the attitude and knowledge only of married women. This might reflect the researchers attempts to be respectful of their contexts, but it is acknowledged that this limits the findings to this group of women.

Lowder et al. (2011) also investigated body image perception in women with prolapse through conducting focus group interviews with 25 women with third degree prolapse. Women in this study reported being self-conscious, different, disgusting, and reported that they tended to isolate themselves from social interactions. Women expressed that they felt less feminine, less desirable, and less attractive which made them avoid intimacy. They experienced the sense of losing their relationship and that they were letting their partners down because they felt that they were handicapped as a result of their prolapse and that their bodies are failing them. Women were ashamed and embarrassed by their condition that they lost interest in daily life activities, but they were hopeful and optimistic that this condition can be fixed. No other studies have reported such a positive outlook toward prolapse. The design of the study provided rich descriptions and offered a window to real life experiences. Women in focus groups felt heard, participated in discussions, and supported each other. Participants were enrolled after attending a consultation for their condition; hence, some have the knowledge that prolapse can be treated surgically which might have affected their general outlook and resilience. Moreover, this study was conducted in the USA and considering the sensitivity of the topic, focus group interviews might not sufficiently address the body image perception of women with prolapse, especially in a conservative culture like Saudi Arabia. For example, women may not feel as able to support each other, share their views freely or even might not volunteer to participate. This is argued because topics related to sexual health are considered sensitive in the context of Saudi Arabia and are rarely discussed.

## 3.5.4. Knowledge about pelvic organ prolapse

Two studies aimed to investigate the knowledge women experiencing symptomatic prolapse have about their condition. The studies used quantitative design to address aims and objectives. Both studies were conducted in the USA and both reported that women have limited knowledge about prolapse and the management options (Mandimika et al. 2014; Good et al. 2013). Good et al. (2013) conducted a cross-sectional study to explore women's knowledge about POP through using a self-developed questionnaire and distributed to 213 English speaking women with no previous hysterectomy aged  $58\pm14$ . Findings showed that women have limited knowledge about prolapse and management options. The validity and reliability of the used questionnaire are unknown; therefore, it is possible that the findings of this study are not generalisable at USA population level.

Conversely, the study of Mandimika et al. (2014) administered a proven, valid, and reliable method: Prolapse and Incontinence Knowledge Questionnaire (PIKQ) (Shah et al. 2008) to a total of 431 women. The findings showed that nearly half of the women had limited knowledge about prolapse. However, there was a large age range between study participants (19-98 years) which affects the applicability of the findings to other specific age groups and limit the generalisability.

Both studies above did not provide sufficient evidence about the knowledge of prolapse among women with symptomatic prolapse. Despite the limitations in both studies, identifying lack of knowledge about POP across women in the USA was unexpected. This is because of the sex education curriculums implemented in schools that has resulted in improving reproductive health outcomes (Hall et al. 2016). Women in Arab and Islamic countries have limited access to formal sexual health knowledge or education compared to women in western societies and therefore such findings about knowledge related to POP might also be identified among Saudi women (DeJong et al. 2005). Although this has been reported in 2005, there is no evidence suggesting that there has been a positive change in Islamic and Arab societies in terms women's access to sexual health education resources. Hence, it is understood that women in Arab societies including Saudi Arabia might also have poor sexual health outcomes due to the apparent lack of knowledge about sexual health (Rahman 2018). It has been stated that lack of knowledge about sexual health causes women to feel vulnerable and unable to make informed decisions about their own health. Thus, it could result in serious threats to women's health and could occasionally contribute to morbidity and mortality (Alomair et al. 2020).

Opposite to the USA, there is a lack of sexual related knowledge and the absence of sex education curriculums in schools in middle eastern societies, due to the taboo surrounding sexual health, many young women report their first menstrual cycle and first sexual encounter to be disturbing (Golchin et al. 2012; Alomair et al. 2021). Conversely, it is reported that women who had sufficient prior knowledge about their menstrual cycle identified their first experience to be positive (Hennegan et al. 2019). In Saudi Arabia, there are no formal resources of knowledge on sexual health for both genders except in Islamic books in schools (Saudi Arabia Ministry of Education 2019). Some religious scholars see that sexual and reproductive health education for unmarried women is against Islamic religious beliefs because religious practices provide protection against sexually transmitted infections (Alomair et al. 2020). Therefore, knowledge about POP is important to be addressed as it may shape women's response to their illness and their healthcare seeking behaviour.

#### 3.5.5. The healthcare seeking behaviour of women with prolapse

The healthcare seeking behaviour of women with prolapse has been explored by several studies. Based on my personal experience as a physiotherapist and the discussions I had with HCPs involved in the management of POP in Saudi Arabia, there was an agreement that Saudi women delay and at times avoid seeking professional support. Nevertheless, there are no studies that explored the healthcare seeking behaviour of women with prolapse in Saudi Arabia. Given the relevance of prolapse to sexual health, it can be assumed that their response is driven by certain contextual factors.

The study of Shrestha et al. (2014) used mixed methods design to investigate the healthcare seeking behaviour of women with prolapse in Nepal. Questionnaires were administered to 107 women diagnosed with grades three and four prolapse, among them 16 women have participated in in-depth interviews. Findings of this study reported that women with prolapse in Nepal avoided seeking healthcare because of the sense of shame which included having no-one to share the problem with, male service providers, fear of stigma and discrimination, and perceiving uterine prolapse as normal consequences of childbirth. Although no sufficient information was given on the questionnaire used in the study, the mixed-method design used added to the credibility of the findings by reporting the barriers to seek healthcare through interviews and confirming the findings by the use of questionnaire. It has been discussed earlier that Nepal has a different religious and cultural background to Saudi Arabia, but there may be some similarities in the social norms imposed in both countries. Therefore, it is possible similar findings will be reported in terms of their barriers to seek professional support particularly in terms of being seen by male physician. Indeed, one study showed that Saudi women have a considerable preference of the presence of a female physician in the emergency department to handle clinical assessment, non-life-threatening cases, and physical examination (Alqufly et al. 2019). This study however did not consider women's perspectives of being treated by a male physician for issues related to sexual health, like prolapse.

The study of Hammad et al. (2018) reported similar findings to the study of Shrestha et al. (2014). This study explored the healthcare seeking behaviour of women with prolapse and it was conducted in the United Arab Emirates (Hammad et al. 2018), a country that shares a similar religious and cultural background with Saudi Arabia. The

findings of this study demonstrated that prolapse affected physical and social activities in addition to praying and sexual relationship. Out of the diagnosed women included in the study, 69 women did not seek healthcare support due to variety of reasons including embarrassment to see a practitioner, being seen by a male practitioner, lack of knowledge about prolapse and the belief that it was a normal condition among women, and lack of awareness of existing treatment options for prolapse. Although this study has a number of methodological limitations such as the use of a non-validated questionnaire and the age of participants that ranged from 18 to 71 years, this study highlighted social barriers to seek healthcare support for prolapse that may reflect the experience of women in Arab and Islamic societies including Saudi Arabia. It has been reported in evidence that Saudi women have limited knowledge about their sexual health which may negatively impact their health outcomes (Alquaiz et al. 2012; Gaferi et al. 2018). One ethnographic study by Al-Zahrani (2011) stated that Saudi women face difficulty in seeking professional help for their sex related health problems due to the cultural taboo around their sexuality. In addition to poor health outcomes, lack of sexual and reproductive health knowledge contributes greatly to negative sexual and reproductive experiences and has been linked with emotional distress and psychological issues for Saudi women (Alomair et al. 2021). Cumulatively, these factors may provide an indication for exploring the healthcare seeking behaviour of Saudi women with POP and gain an understanding of how culture might be informing their experience but perhaps using a different method of investigation. This is because of the non-validated questionnaire used in this study could be subject to measurement errors and it would be challenging to draw conclusion with total confidence (Dowrick et al. 2015).

Delaying or not seeking professional support has also been reported in Westernised societies like Sweden (Pakbaz et al. 2010), but this was attributed to limited knowledge about the condition. This study aimed to investigate the healthcare seeking behaviour of women diagnosed with prolapse in Sweden. Self-developed questionnaires were also administered to a total of 561 women, among them 214 were diagnosed with prolapse, 186 had undergone a hysterectomy, and 161 had urinary incontinence. The study demonstrated that women with prolapse did not perceive prolapse to be an issue that needs intervention as compared to urinary incontinence. Moreover, one in five women with POP did not know that prolapse symptoms are caused by the prolapse. Women

with prolapse had also reported fewer sources of information compared to other groups. This study highlighted some important issues, firstly, women are often unaware that prolapse symptoms indicate a serious issue and that such issues are not normal. Secondly, information resources for women with prolapse are very limited which indicates that the problem is hidden and not addressed in some societies including westernised societies. In such circumstances, it can be assumed that the overall experience of the condition would be personal to each women but also shared due to the shared cultural background (Husserl 1970). In addition, urinary incontinence has been well publicized through advertising anti-cholinergic medications and sanitary pads, however, in contrast, no or little publicity exists for prolapse. Some limitations were noted in this study that were not clarified by the authors. For example, as the questionnaire was developed for investigating the perception and healthcare seeking behaviour of women diagnosed with prolapse, it can be assumed that some prolapse related questions might be irrelevant to women who had urinary incontinence and hysterectomy. Nevertheless, the findings of this study demonstrated that lack of knowledge and limitation in educational resources about sexual health is disadvantageous to women. It has been suggested that women in Saudi have apparent misconceptions regarding their sexual health due to the limitation in access to informative resources and their dependence on seeking health information from the internet or from their mothers or teachers (Gaferi et al. 2018).

A further qualitative study was conducted by (Pakbaz et al. 2010) in Sweden. Pakbaz et al. (2010) aimed to elucidate the experience of women with vaginal prolapse prior to surgical intervention. The study incorporated the method of in-depth interviews with 14 women scheduled for vaginal reconstruction surgery and their age ranged from 42 to79 years old. The authors of this study have different professional backgrounds; a urogynecologist, midwife, gynaecologist, and obstetrician, this may have improved the findings validity as it provided different perspectives and insight from range of multidisciplinary health professionals. Findings of this study identified two categories and 11 sub-categories from the data. The first category was the obstacles to seeking healthcare and included factors such as an absence of information as women with prolapse often could not address what they were suffering from. Women also reported blaming themselves for not seeking healthcare at an early stage as they considered that their impediment with prolapse was going to be overcome. Feeling ignored initially by

doctors was also reported by women that were experiencing the symptoms of prolapse, moreover, they indicated that their symptoms were not confirmed by physicians as a prolapse at first. Women also expressed prolapse as being a covert condition as it is invisible to others. Establishing coping strategies to overcome the symptoms also delayed women in seeking healthcare advice. Women also reported de-prioritising their own health as an obstacle to healthcare seeking; indeed, some women indicated that prolapse is of less importance when compared to other medical conditions. Facilitators to seeking healthcare were as follows: support from others, difficulty accepting the aging body, feeling sexually unattractive, feeling their body was 'unnatural', and reaching the point of action. Women included in this study were already assigned for surgery so their views may differ to women who were not assigned for corrective surgeries. It is possible that assigning for surgical intervention impacted their perception of prolapse. However, the findings of this study are relevant to the proposed research question and identified some important issues that need to be addressed to facilitate women's healthcare seeking behaviour. Attention must be given to the factors identified as obstacles to seek help, such as absence of information about prolapse that resulted in making a hidden issue and women thinking that it would resolve with no intervention. Addressing these issues will be helpful for HCPs and they can work to overcome them. In terms of facilitators to seeking healthcare, it can be indicated that women experience the consequences of prolapse for a relatively long time before seeking healthcare. Clearly, the onset of prolapse is accompanied by multiple symptoms that cannot be ignored. Despite the bothersome associated with symptoms, women in this study chose not to seek healthcare support as soon as they experienced the symptoms and instead established coping strategies to live with the condition. The method of investigation used in this study presents an in-depth understanding of women's experiences of POP and healthcare seeking behaviour.

Basu et al. (2011) identified women's preferences for the treatment of pelvic floor disorders. This qualitative study included 16 women aged between 48 to 70; among them, nine had Stress Urinary Incontinence (SUI), five had prolapse and two had both SUI and prolapse. The women with SUI perceived their symptoms to be embarrassing and extremely bothering and ascribed their opinions regarding the acceptability of the different treatment options for this. The ultimate goal that these women wished to achieve was for their quality of life to be as it was before they developed symptoms of

incontinence. Women with prolapse tended to be more focused on the pros and cons of the treatments on themselves, rather than the effect the outcome of treatment may have on their quality of life. Both the women with SUI and the women with prolapse expressed a wish for a treatment that did not require continued input, and surgical solutions were deemed more acceptable because they were perceived as a 'one-off' treatment. Women with prolapse were focused on the complications of the surgical treatments. Although they talked at some length about potential risks, few completely disregarded Mesh-augmented repairs. They were generally uncertain about the acceptability of the Mesh-augmented repairs and wished to know more details about complications. It has been reported that transvaginal Mesh repairs for POP pose women to experience pain and bleeding and could further cause serious complications like erosion and formation of fistula (Australian Commission on Safety and Quality in Health Care 2018). There is no reference to support my argument but based on my discussions with HCPs, this procedure is still performed by urogynaecology physicians in Saudi Arabia as one of the primary methods of management for prolapse. Women in the study indicated that they preferred surgical interventions because they thought it would put an end to their illness. It could be that they would have different opinions if they were aware of the complications of surgical interventions of prolapse that includes the possibility of repeating the procedure in a couple of years. This study defines how women's expectations of treatment and perceptions of actual treatment modalities interact in decision-making. In addition, the findings of this study are of importance in the context of political pressures to promote patient choice that is conditioned by patient education. This will help patients to make informed decisions about their health.

In the study of Low et al (2012), the authors aimed to identify the experience of women diagnosed with pelvic organ prolapse who had sought medical services for their condition. The scope of this study was to identify the limitations in the understanding of women's experience of prolapse in healthcare environments. Low et al. (2012) conducted semi-structured interviews with 13 American women diagnosed with pelvic organ prolapse, five of whom had surgical reconstruction. The mean age of the included women was 57 years and interviews were conducted via phone. Findings of this study were reported using the Authoritative Knowledge Framework by Jordan (1992), and three themes were identified: the first theme was that authoritative knowledge is held by the healthcare provider as women seek opinions of healthcare providers due to lack

of knowledge and information regarding pelvic organ prolapse. Indeed, some women were not experiencing any symptoms and were diagnosed with prolapse. The second theme was that healthcare providers authoritative knowledge is valued over experiential knowledge. The third theme was that authoritative knowledge is constructed and reinforced by healthcare providers and women themselves accept what healthcare providers offer even if it contradicts their experience. This study is valuable to clinical practice because it addresses some important issues that are often missed by healthcare professionals obtaining a biomedical perspective in practice such as assessing and treating patients with an objective lens and addressing their individualistic needs. It highlighted that healthcare providers need to be more subjective and consider the biopsychosocial model or patient-cantered approaches rather than the biomedical model when it comes to treating a patient with POP as every case is different. This study also indicated that women need to be educated about prolapse, so they can communicate effectively with healthcare providers. Nevertheless, there are some methodological concerns such as interviews were conducted via phone. Low et al. (2012) argued that participants answered more honestly using this approach and suggested that it might allow the patients to disclose such information in relaxed manner. However, the absence of visual cues via telephone may result in loss of contextual and non-verbal data and compromise rapport, probing, and interpretation of responses (Novick, 2008). This study further highlighted the importance of exploring the views of women with POP in Saudi Arabia and understand the implication of lack of sexual health knowledge on the patient-physician relationship and further understand how this would affect their response to advice given to them by their physician.

## 3.6. Chapter summary

In this chapter, the relevant literature has been reviewed and the gap within the literature has been explored. The literature about the all over experience of POP was explored. Some of the studies aimed to investigate specific issues relevant to prolapse for example the sexual implications of prolapse and how it affected women, the knowledge women had about prolapse, and their healthcare seeking behaviour. Other studies aimed to assess quality of life of women with prolapse using different tools. All these studies have been incorporated in this review and provided broader perspective about the condition. The findings of these studies have been discussed in relation to the context

of Saudi Arabia and compared and contrasted to the realities of Saudi women to conceptualise how the experience of women of POP from different parts of the world may or may not relate to Saudi women. This has highlighted the need to approach women themselves and explore their experience of POP. In addition, it was concluded that obtaining a qualitative methodology will be suitable to address the experience of Saudi women and provide a wider perspective. The next chapter is set to discuss the research design used in this study to address the identified gaps in the current literature by considering the aims and objectives.

# 4. Chapter Four: Research Design

## 4.1.Introduction

This chapter seeks to outline the methodology and the methodological approach undertaken to answer the research question. It demonstrates the researcher's ontological and epistemological stances that guided the choice of methodology, and it further provides justifications for choosing qualitative research design, primarily a phenomenological approach to analysis, permitting exploration of the experience of Saudi women living with pelvic organ prolapse.

## 4.2. Study aims and objectives

The aim of this study is to explore the lived experience of Saudi women around the age of menopause with pelvic organ prolapse.

The objectives of the study are to:

- Explore if the culture in Saudi Arabia in shaping impact the experience of pelvic organ prolapse.
- Be respectful of the potential individuality and subjectivity of the experience due to the sensitivity and hidden nature of prolapse in Saudi Arabia.
- Provide recommendations for healthcare service provision based on the experience of women with prolapse through disseminating information so that other healthcare professionals can better understand women's' experiences.

#### 4.3. A brief overview of study methodology

The issue of prolapse is under-researched in Saudi Arabia and it is noted that the healthcare service provision for women with prolapse in the western province of Saudi Arabia is broadly limited to medical interventions particularly surgical interventions. Whereas conservative treatment options such as physiotherapy are only reported to be available at three governmental hospitals out of nine hospitals in the city of Jeddah. Healthcare professionals in Saudi Arabia during the informal discussions I had with them in the phase of planning the study said that they

consider physiotherapy service provision is determined by the response of women to their illness. As women are observed to seek support at late stages of prolapse, surgical interventions are suitable at that stage making physiotherapy a less favourable option, therefore, affecting the profession of women's health physiotherapy in Saudi Arabia and service provision. In order to conceptualise the issue and understand the experience of women that maybe informing their response to prolapse, women with prolapse were invited to participate in a discussion and be asked about their condition. Hence, this study focuses on the experience of Saudi women with prolapse. By increasing understanding of such discussion, it is hoped that recommendations for clinical practice can be identified in order to help address the needs of women with prolapse.

This qualitative study was initially set out to utilise a phenomenological lens to explore the experience of Saudi women with prolapse. This is deemed most appropriate because it allows the researcher to ask participants about their experience of prolapse and their sense-making of their experience (Schutz 1972). Given the taboo of discussing sexual health related issues in Saudi Arabia as proposed in chapter (2), it can be understood that prolapse is a sensitive health condition in the context of Saudi Arabia. Caelli (2001) stated that adopting a phenomenological methodology when discussing sensitive topics may allow the participants to share their thoughts and feelings with the researcher. These topics may not be openly discussed and result in participants' experiences with the given phenomenon being personal and subjective. The researcher here acknowledges the potential individuality of experience, but with the effort of the researcher, a shared experience can be identified to reach cohesive and robust findings

A qualitative approach was considered to explore the experience of Saudi women with prolapse. Asking women about their experience was thought to be the most appropriate way of addressing the research aims, gaining understanding and rationalisation of experience; therefore, semi-structured interviews were used with Saudi women with prolapse. Prolapse is considered a sensitive topic in the context of Saudi Arabia, choosing semi-structured interviews and having an interview guide was to facilitate the discussion and give focus to the interview. Women with symptomatic prolapse were recruited from one of the major hospitals in the western province of Saudi Arabia. Participants were initially sought from the community, who have not sought professional support through distributing flyers at public places visited by women and with the use of social media platforms "Twitter". Women did not volunteer to take part in the study through these two methods. Therefore, the plan was adjusted to recruit participants who had sought professional support but did not receive surgical management for prolapse.

Eight semi-structured interviews were conducted with women who agreed to participate in the study. Women had previously been diagnosed to have prolapse and the triage nurse individually asked each woman about the reason for her visit to the urogynaecology clinic before inviting her to the study.

The interviews were conducted in Arabic language. Following the completion of data collection, each interview was transcribed in Arabic and then translated into English language. This was personally undertaken with the support of an Arabic language speaking friend who has a master's degree in English. The initial analysis of the data used interpretative phenomenological analysis. This was not fully achieved as linguistic analysis proved impossible. Prolapse was a culturally hidden issue and women expressed their experiences differently, but as their narratives were translated, some of the meanings were lost in translation (see chapter nine). Therefore, a second analysis was undertaken using reflexive thematic analysis. The flexibility in the analysis permitted by reflexive thematic analysis accepted my epistemological and ontological stances and acknowledged my close attachment to my data following attempts of interpretative phenomenological analysis; therefore, the analysis was done at individual level where themes were generated from each transcript moving to next case and then generating themes at group level through identifying the shared themes. This has aided in increasing the depth of analysis and ensured that the voices of these women are still heard.

## 4.4. Research paradigm and philosophical standpoint

It is noted that researchers in all healthcare professions face a common issue when deciding what methodological approach to use to answer their research question. In essence, a wide range of frameworks can be adopted to answer different types of research questions, but research paradigm helps in guiding the researchers in identifying the suitable methodology to gain the data needed to answer the research question. Thus, it can be stated that understanding the research paradigm is paramount for PhD researchers to design rigorous research that will help them to answer the research question.

A paradigm is defined as a philosophical way of thinking (Petty et al. 2012a). Applied to research, a paradigm represents the set of beliefs and assumptions about the nature of reality that informs how the research question should be addressed (Kivunja et al. 2017). A research paradigm reflects the principles that shape the researcher's world and how they act within it, thus, it is argued that stating a research paradigm is essential due to its significant influence on the overall research process (Gringeri et al. 2013).

The current research question will be addressed using a qualitative methodology; qualitative research broadly encompasses a number of different research methods underpinned by different research paradigms and theories (Hadi and Closs 2016). A paradigm however does not necessarily represent a fixed set of rules. Piele (1988) noted that a paradigm represents loose and developing guidelines that assist the ongoing production and resolution of research problems. The choice of methods needs to be transparent and align with chosen paradigm and each researcher ought to have an argument to support their position. There is no right or wrong, and researcher can ground their inquiries in a number of paradigms, the choice depends on what the researcher feels is more or less useful in a particular situation.

This project's research question is considered from an interpretivist paradigm. Guba and Lincoln (1994) indicated that the choice of research paradigm is determined by the way the researcher responds to three basic questions: ontology, epistemology, and methodology. It is however argued that researchers need to develop a reflexive awareness of the research questions they are asking (Willig 2012). In addition, the choice of methodological approach is affected by the researcher's ontological and epistemological assumptions. In order to ensure transparency and rigour of this thesis, demonstrate my worldview, and rationale for choosing this paradigm, these three components of the research paradigm will be discussed within the context of my research question.

Hudson and Ozanne (1988) defined ontology as the nature of the knowledge created by contextual understanding. Carson et al. (2001) viewed ontology as a philosophical study of the nature of reality. Ontology ought to examine the underlying belief system of the researcher. The philosophical assumptions of the nature of reality guide the interpretation of data gathered. Indeed, the assumptions we use to make sense of the world around us help to orientate our thinking about research problems, their significance, and how to approach it (Kivunja et al. 2017). Mc Manus et al. (2017) have divided the concepts of ontology into two main categories that are: objectivism and subjectivism. According to Kuhn (1962), the objectivist ontological perspective asserts that there is an existing objective reality which can be understood through the laws that legitimise it. This concept is often associated with quantitative methodological approaches that seek to measure those realities. Conversely, the subjectivist ontological perspective asserts that knowledge about reality is created by contextual and social understanding; thus, it is mostly associated with qualitative methodologies and understanding of societal viewpoints (Mc Manus et al. 2017).

The subjectivist ontological perspective is suitable to be adopted for the current study. This is because little is known in terms of the lived experience of women with prolapse in Saudi Arabia. The reality of the experience therefore cannot be quantified or measured through the available quantitative instruments that may require cross-cultural adaptation first. As seen in chapter (3), a number of studies have looked at the experience of women with prolapse in different parts of the world, but a large proportion of studies were conducted in western countries or countries that have different cultural and religious backgrounds from Saudi Arabia. These studies have suggested that the way women perceive their condition and respond to it aligns with their cultural backgrounds and social norms. This may highlight the need of subjectively exploring the experience of Saudi women with prolapse.

Epistemology is concerned with what counts as knowledge within the world (Cooksey and McDonald 2019). It is about how researchers attempt to understand

and capture the nature of knowledge (Carson et al. 2001). It seeks the nature of knowledge and how to approach this knowledge. There are two main philosophies to epistemologically achieve an understanding of the nature of knowledge which are: positivism and interpretivism (Mc Manus et al. 2017).

A positivist philosophical stance is suitable to be used with quantitative research methods where the aim of the research is to collect numerical data and answer questions involving numerical accuracy such as in quantitative surveys. It is believed that healthcare researchers can advance their knowledge within positivist framework (Broom and Willis 2007). One feature of positivism that is highlighted in literature is that the researcher lays down hypotheses from a scientific perspective and tests these hypotheses. Thus, research under positivist framework is often used to inform evidence-based clinical practice such as randomised control trials and retrospective cohorts. Positivism is not adopted as an epistemological stance in this study. This is because one of the requirements of using a positivist paradigm is to maintain minimal interaction with the research participants. This is not possible given the aim and objectives of the current study that seeks to achieve an understanding of the participants' experience with prolapse.

In contrast, an interpretivist philosophical stance shifts the perspective from observing participants and recording objective data, to seeking an understanding of participants' standpoints and exploring their sense-making using a qualitative methodology (Broom and Willis 2007). The aim and objectives of this study will be addressed from an interpretive stance. It is argued that the "nature of the interpretive paradigm rejects a foundational base to knowledge" (Scotland 2012, p.12). in addition, one common feature of the interpretivism paradigm is that the fragmented knowledge gained under this paradigm is not generalisable to another context.

The current study aims to explore and understand the lived experience of pelvic organ prolapse in Saudi Arabia. The most suitable way to do so is through subjectively understanding how each woman perceives the condition she is experiencing and how she makes sense of her experience within her context. It could be argued that understanding the experience of the condition through the accounts of Saudi women will only provide a description of the condition without acknowledging any potential personal or societal differences across the participants. Hence, understanding the lived experience of prolapse through the accounts of Saudi women perhaps is better achieved through applying an interpretative lens that accepts that accounts provided by women are a result of interpretation of their relatedness to their world, but are also uniquely embodied in each one of them.

Methodology refers to the research approach either quantitative, qualitative or a combination of the two, mixed methods. Research design is about methods and about how the data will be gained in order to answer the given research question; it includes sample size, data collection and how the data will be managed or analysed (Al-Saadi 2014). Interpretative phenomenological analysis was initially chosen as a methodological approach for guiding the research process and the analysis of data. This however changed during the analysis phase because it was found that IPA was not suitable for analysing the data that had been generated. This change to a reflexive thematic analysis will be discussed during the discussion of how the data were analysed (see chapter 6).

## 4.4.1. Interpretivist paradigm

Using the interpretivist paradigm allows researchers to view the world through the perceptions and experiences of the study participants (Thanh and Thanh 2015). This paradigm is concerned with broad and general questions, such as 'what' and 'how' (Silverman 2017) i.e., what is the meaning of living with POP, and how you make sense of it. In order to seek an answer to the research question, the investigator who follows an interpretivist paradigm uses those experiences to construct and interpret their understanding from gathered data.

This study seeks to explore the lived experience of Saudi women with POP around the age of menopause. Social constructivism is the sociologists' preferred paradigm to explore the experiential component of an illness as it is predominantly used in research compared to other qualitative paradigms. However, understanding how society constructs knowledge about prolapse using approaches like grounded theory may be challenging for a couple of reasons. Firstly, grounded theory is often used when little is known about a phenomenon with the primary aim of generating a theory that seeks to explain it. My aim in the current study is not to generate a theory about the experience of prolapse rather it is to gain an understanding of the experience in the context of Saudi Arabia. Secondly, iterative data collection and analysis and reaching saturation is essential to generating theory. This may be impossible to achieve given the hidden nature of the topic under investigation in the context of Saudi Arabia. Thirdly, Strauss and Corbin (1998) argue that it is of importance to start a grounded exploration with very little previous knowledge as having prior knowledge of the area under study will make the use of grounded theory very difficult. Given my professional and cultural background, I already had considerable knowledge about prolapse and the social demographics of Saudi Arabia. In addition, I had read a significant amount of literature about the condition. It was therefore not pragmatic to use a grounded theory approach. This study did not also seek to generate a theory from data, as such grounded theory was not the method of choice. The lived experience of Saudi women with prolapse will be addressed using qualitative research design but under an interpretive philosophical framework. To support the use of an interpretive paradigm, more characteristics of interpretivism are further clarified.

Although the interpretivist paradigm is not a dominant model of research, it is observed that it is gaining a considerable influence, because it can accommodate multiple perspectives and versions of truths (Conroy 2003). This is because interpretivism is an epistemological stance, it is concerned with how knowledge is created. This paradigm recognises subjectivity in the experience.

Interpretivists believe that an understanding of the context in which any form of research is conducted is critical to the interpretation of the data gathered (Willis et al. 2007). Indeed, interpretivism usually seeks to understand a particular context, and the core belief of the interpretive paradigm is that the 'reality is socially constructed' (Mertens 2007, p.216), which means that the reality as meaning and value are subjective and experiential, which are created, not discovered. Contextualising this to the current study, this suggests that the meaning of the experience of living with prolapse in Saudi Arabia is mainly constructed by women who experienced the condition themselves. They are the only ones to know what it is like to experience prolapse in Saudi Arabia. Nevertheless, because it is a

culturally sensitive issue given its link to sexual health, there might be individuality in the experiences and potential differences among women and their perspectives. Interpretivism accepts that and seeks those multiple perspectives.

The acceptance of multiple perspectives in interpretivism will further help to develop a more comprehensive understanding of the situation (Klein and Myers 2001). According to Koch (1995), interpretative research represents a holistic study of multiple realities. This is relevant to the nature of the underpinning ontological perspective. Interpretive research is conducted within a framework which essentially originates from the subjective ontological perspective. Subjectivism, as proposed earlier, assumes that there are no single but multiple realities that can all be interpreted and reconfigured in many ways by those who have experienced a phenomenon and also the researcher who is interpreting the study data.

Interpretive research allows researchers to understand experiences rather than to look for causal relationships between variants. Lopez and Willis (2004) consider this to be particularly helpful when exploring the lived experience of people within a healthcare setting, allowing the context of the experience and the understandings associated with it to be facilitated. Brown et al. (2012) claimed that subjective meanings are not only based on individuals' views but are also the product of social interaction with others, and historical and cultural customs that influence individuals' lives. Starks and Brown Trinidad (2007) view the researcher as the instrument for analysis across all phases of a qualitative research project. Indeed, the transmission of assumptions, values, interests, emotions and theories (or what is referred to collectively as the researcher's preconceptions) is inevitable, within and across the research project. These preconceptions inevitably influence how data are gathered, interpreted and presented (Tufford and Newman 2012). Heidegger argued that an in-depth understanding of a lived experience is an interpretative process and that bracketing out the researcher's preconceptions was neither possible nor desirable (Cohen and Omery 1994; Heidegger 1962). Heidegger, thus, adopted the position of being in the world, where contextual interpretation and meaning were sought and valued (Gearing 2004).

Thus, my role as a researcher here will be to establish an interactive link with study participants in order to understand the lived experience from the point of view of women who are experiencing the symptoms of prolapse. Additionally, the researcher and the social world impact each other, the knowledge generated will be a product of my and the study participants' interpretations. Interpretivism accepts the relationship between me as a researcher and the social world, and the meaningfulness of the findings is dependent on my interpretations of the participants' accounts. The meanings held by individuals can be formed through interaction with others and from a specific culture, this broad view is often explored (Molden and Dweck 2006). The interpretivist paradigm acknowledges my experiences as a researcher, this needs to be explicit in relation to the influence that these will have on the interpretation, a process referred to as the reflexivity (Haynes 2012). The values and biases I bring to the study will be made explicit through the use of reflexive journal (see appendix H), to enable the reader to contextualise the study (Haynes 2012). The results will be the product of my attempt to understand a phenomenon as portrayed by the participants'. Specifically, doing this research under an interpretivist paradigm will allow me to recognise my role as a researcher, in terms of exploring my world by interpreting the understanding the experience of Saudi women living with prolapse. Knowledge generated from the research in interpretivist paradigm will have been coconstructed by the participants and researcher and will bear the mark of this process such that the knowledge cannot be assumed to be generalized but may be transferrable to other situations (Lewis et al. 2003).

# 4.5. Choice of study design and rationale

Research designs are broadly categorised into qualitative and quantitative approaches. Quantitative research design enables the researcher to address the research question using objective methods (Robson 2002). Moreover, quantitative approaches draw information from a targeted population and involve the use of percentages, charts and hypotheses testing using numerical data (Robson 2002). Mc Manus et al. (2017) suggested that quantitative research is often used in positivist research whilst qualitative studies are mostly aligned with the interpretivist paradigm.

Qualitative methods in contrast are mainly aimed at understanding human behaviours and attitudes through interpreting situations (Green and Thorogood 2014). Punch (2013) defined qualitative research as empirical research where the data are not in the form of numbers. Qualitative methods allow the gathering of more depth and meaning, respecting an individual's beliefs and experiences (Newell and Burnard 2010), as opposed to a quantitative approach.

The choice of design merely depends on the type of question being asked (Creswell et al., 2011), and it is also influenced by the epistemological stance that the researcher holds. The central aim of this thesis is to achieve an understanding of the lived experience of prolapse from the perspectives of Saudi women around the age of menopause. Such understanding of thoughts, experiences and reasoning suggested that the qualitative approach is most suitable for this research (Merriam 2002). Qualitative research design is deemed most appropriate to address the study aim and objectives for three reasons: firstly, qualitative research stems from social sciences that were essentially designed to help understand a given experience using participants' narratives and improve our understanding of social phenomenon (Creswell 2006). Hence, approaching Saudi women and listening to their stories will aid in developing an understanding of their lived experience with prolapse and facilitate exploration of whether the culture in Saudi Arabia has a unique impact on their experience. During the scoping review (chapter 3), it was noted that studies that explored the experience of women with POP, which adopted qualitative methodologies presented a richer description of the experience compared to studies that used quantitative methods.

The second rationale for choosing a qualitative research design is that qualitative research is well-suited to an exploratory investigation where little is known or understood about a given phenomenon, or where the topic under investigation is under-researched (Creswell 2006). Literature about prolapse in Saudi Arabia is scant; an extensive search on multiple databases identified no relevant studies. Additionally, anecdotal evidence from healthcare professionals involved in the management of the condition in Saudi Arabia indicated that four governmental hospitals in the city of Jeddah in Saudi Arabia are equipped for the management of prolapse: broadly, surgical management. Few hospitals are equipped with

physiotherapy management resources. Saudi women with prolapse are rarely seen seeking professional support and even then, leaving this until the very late stages which affect the utilisation of physiotherapy services available for them and service provision. This potentially highlights the importance of approaching women themselves and subjectively exploring their lived experience of the condition. In addition, it is also an indication that these women's beliefs and values must be explored to further understand how their beliefs s might be affecting them and their behaviour. Listening to their stories will enable an insider perspective and understanding of their lived experience, far better achieved by using a qualitative approach.

The third justification for choosing qualitative research design over quantitative is that the topic under investigation can be perceived as sensitive; indeed, POP has been identified as a sensitive condition due to its link to sexual behaviour (Barber et al. 2002). Moreover, reflecting on the cultural and social norms in Saudi Arabia suggested that the condition is more sensitive because of the taboo of discussing sexual health issues in Saudi Arabia, as presented in chapter (3). It is suggested that qualitative research methods are more suitable for researching sensitive topics although this has proven challenging in previous sensitive studies because often participants are of a hidden population or hard to reach (Dickson-Swift et al. 2007)

Using qualitative methodological approaches and using participants' narratives can be argued to lack objectivity, as the social meanings held by women living with the condition in Saudi Arabia will be of subjective nature; therefore, it will limit the generalizability of findings. Nevertheless, qualitative research does not aim for seeking objectivity and generalisability (Leung 2015), rather it seeks to understand a social phenomenon in natural settings, hence it intentionally seeks subjective meanings and views of participants about that phenomenon.

Quantitative research conversely helps to explain a phenomenon by collecting numerical data. It tests hypotheses, controls variables, measures and identifies cause and effect relationships, aiming to generalise findings and predict future events through statistical analysis (Petty et al. 2012b). Quantitative research design has not been employed in this study because it has a different epistemological and philosophical stance. Being guided by positivism, quantitative research holds the

stance that the scientific method is the only way to establish truth and objective reality based on the belief that science is the only foundation for true knowledge (Petty et al. 2012b). Moreover, this study seeks to explore lived experience, the concept of experience itself is subjective and cannot be quantified particularly if little is known about the phenomenon under investigation (O'Day and Killeen 2002). It can be argued that it takes more than standard quantitative research techniques to fully explore the richness of human experience, it can be stated that qualitative research seeks meaning and understanding of processes and phenomena, with attention to narratives, personal experiences, and language. The aim of qualitative research is not to identify a cause-and-effect relationship through numbers but rather in themes that emerge from narratives indicative of common human experiences; thus, it correlates with the study aim.

#### 4.6. Interpretative phenomenological analysis

# 4.6.1. Theoretical foundations of IPA

IPA is an experiential qualitative approach with a predominantly psychological interest in how people make sense of their lived experiences. Hermeneutic phenomenology and idiography are the key philosophies underpinning IPA (Smith and Osborn 2007; Larkin and Thompson 2012). IPA seeks to collect rich reflective accounts of how a participant makes sense of a particular experience while focusing on aspects that are often unobserved in daily life (Finlay 2011). The philosophical roots of IPA are closely aligned with traditional Husselarian phenomenology that seeks objective meanings but it also integrates the ideas of Hideggerian phenomenology that recognises that how things appear is a result of a series of ongoing interpretations of the participants' life world (Smith 2012).

In addition to Husserl and Heidegger, IPA phenomenology also involves the philosophical contribution of several phenomenological frameworks such as Marleau-Ponty's concept of worldliness which focuses on existential meaning, Sartre's theory of nothingness that examines participant-context interaction, and Schleiermacher and Gadamer's theories that are concerned with historical, political, and contextual forces. Combined together, these theories assist in explaining the experiential phenomenon through layering depth to the interpretative lens to phenomenological inquiry. Hence, the analytical process in

IPA is three levelled: descriptive, linguistic, and conceptual (Smith and Osborn 2007)

The commitment of IPA to idiography is what extends it beyond traditional phenomenology as an approach to explore the lived experience. Comparing IPA to traditional phenomenological approaches, it is evident that Husserl's transcendental phenomenology emphasises on explicating the essence of a phenomenon and exploring how a phenomenon is lived and perceived by a particular group of people is the tenet of Heidegger's hermeneutic phenomenology (Allan and Eatough 2016). Whereas in IPA, given its idiographic focus, each participant is valued, and this entitles the researcher to conduct a deep detailed single case analysis before moving to the next case and looking for convergence and divergence across participants' experiences. This is because women would all have individual stories and therefore this was anticipated to be the best way to make their individual voices heard.

#### 4.6.2. Justification for the choice of IPA

It was planned to use IPA within this thesis because of its permittance of an indepth analysis on the individual level followed by group level analysis. The research question aims to understand the experience of a sensitive condition in a conservative culture; hence, it seeks to know the uniquely embodied lived experience of each woman. Traditional phenomenological approaches prioritise similarities in the phenomenon of interest over individual accounts, but IPA does not. It acknowledges that participants might share an experience in common but interpret them radically differently due to personal and contextual factors. This calls for individual level analysis to uncover information and culturally embedded concepts that could not be assessed by observation.

It was planned that the research aims and objectives would be addressed using IPA as a theoretical framework, hence IPA guided the study process in terms of sampling strategy and data collection. However, during the analysis process, it became clear that due to the hidden nature of the topic, the influence of cultural norms and the difficulties in gaining data which would lend itself to IPA analysis the decision was taken to utilise a reflexive thematic analysis, a decision which will be presented in chapter (6).

IPA was proposed by Smith et al. (2006) as a method to explore lived experience through entering a process of data collection and analysis (Reid et al. 2005). It has gained significance as a methodological inquiry in health and psychology to understand the experience of chronic illnesses. Heidegger's hermeneutic phenomenology greatly influenced IPA in terms of capturing lived experience, a person being bound to context, and that context is an important part of a person's identity and how they give meaning to their experiences (Larkin and Thompson 2012). An IPA researcher tries to obtain an insider perspective of participants' experience taking into consideration that access is partial or incomplete due to the complexity of individual experience. Indeed, access to participants' worlds relies on the researcher's own conceptions in addition to reflective accounts of participants (Smith and Osborn 2007). Hence, the analysis is a result of a relationship between the researcher, subject matter, and participants (Sydor 2010). Therefore, the participants understanding of their experience in their world is discovered using IPA while acknowledging that approaching it lacks objective reality (Smith 2012).

# 4.6.3. Why IPA in preference to other qualitative methodologies

## 4.6.3.1.The role of the researcher in IPA

IPA is described as a subjective research approach (Smith and Osborn 2007), indeed it is reported that two analysts working with the same data would end up with different interpretation. My role as a researcher in IPA is equally important to the meaning making of participants. The process of data analysis in IPA is described as double hermeneutic (Smith and Osborn 2007). IPA was at first chosen for this study because it acknowledges the role of the researcher in interpreting the data and developing a phenomenological picture of a lived experience. My interpretations under IPA are an integral part of the analysis, my beliefs, understanding, and preconceptions are acknowledged and accepted to be affecting the analysis. IPA embraces my influence as a researcher on the findings and, opposing Husserl's phenomenology, it recognises that bracketing one's preconception is impossible and the "essence" of an experience is captured through

the analysis of participants' lived experience that is shaped by the researcher's interpretations or as proposed by Smith (2012, p.40):

"The participant is trying to make sense of their personal and social world; the researcher is trying to make sense of the participant trying to make sense of their personal and social world"

Thus, the first rationale for choosing IPA is that it seemed appropriate as it accepts my impact on the data acknowledging that interpretation of the data is the outcome of me belonging to the world and trying to make sense of the participants' world.

# 4.6.3.2. The idiographic commitment of IPA

Consistent with its phenomenological origin in addition to theories of interpretation, IPA is concerned with empathic and questioning hermeneutics in what is described as double hermeneutic (Smith and Osborn 2007). Therefore, IPA is empathic in terms of how the researcher tries to put themself in the participant's shoes to understand what it is like to experience a given phenomenon from a participant's viewpoint. This moves me to the second rationale for initially choosing IPA, its commitment to the idiographic level of analysis (Smith 2004). IPA requires a small homogenous sample that facilitates detailed in-depth case by case analysis allowing to establish deeper understanding of an experience, that could be shared with others but cannot be generalised given its complexity and individuality.

The idiographic component of IPA is essentially linked to Husserl's phenomenology that aims to capture the essence of a phenomenon. Due to the sensitivity of the topic under investigation in the context of Saudi Arabia, it is inevitable that the experience of POP and how women understand and feel about living with it will be varied even with a small homogenous group. Nevertheless, IPA accepts these multiple different views, and due to its idiographic commitment, each participant case is given considerable attention during analysis and given voice to ensure that her voice is heard (Larkin and Thompson 2012) in order to first capture what is unique about her experience followed by identifying the shared experience.

# 4.6.3.3.IPA as a framework

IPA provides a framework to underpin the practical work of phenomenology. As a novice researcher in the field of phenomenology, this was of particular importance. Being characterised as double hermeneutic, IPA study aims to describe participants' world by focusing on experience, life events, language, culture and relationship, followed by an interpretative analysis that shifts the description of the data to a more critical and conceptual sense making (Larkin et al. 2019). This sense making draws upon interpretation grounded in the accounts of the participants through bringing what is normally hidden into the light (Shinebourne 2011). The IPA framework does not represent a fixed set of steps that should be followed, rather it is a flexible approach that provides guidance for inexperienced IPA researchers. In this thesis, the decision of using IPA was to provide a structure for exploring the lived experience. Participants' accounts are viewed as a window to their inner state, but access to their experience is complex and partial, yet IPA provides access to a near experience image.

# 4.7. Chapter summary

This thesis is grounded in the interpretivist paradigm. IPA was chosen as a methodological approach to address study aims and objectives because it accepts the subjectivity of the experience of pelvic organ prolapse due to the sensitivity in the context, and also acknowledges my role as a researcher in the interpretation of the findings. IPA was however not subsequently utilised to analyse the study data, and reflexive thematic analysis was chosen instead. The next chapter discusses the study methods in terms of sampling, recruitment, and data collection that was guided by IPA.

# 5. Chapter Five: Study Methods

## **5.1.Introduction**

This chapter represents the study process in terms of how the study was conducted. Because IPA was initially selected as a methodological approach to address the study aims and objectives, the participants' sampling, recruitment, and the choice of data collection method presented below were guided by IPA.

# **5.2.Sampling and Recruitment**

# 5.2.1. Sampling

Sampling in research is the process of participant selection for the purpose of being studied (Martínez-Mesa et al. 2016). The more explicitly described the study population is, the more transparent the findings can be (Etikan 2016). Making sure that the sample is the most appropriate for a study is necessary in establishing how robust a study will be (Hammersley and Mairs 2004).

In quantitative research, random sampling is reported to be the most appropriate sampling technique. This is due to the nature of quantitative research that seeks generalisability by ensuring that each level within the population has an equal chance of being selected. Qualitative research, as opposed to quantitative research, adopts non-random sampling techniques. Patton (2007) stated that non-randomised sampling permits qualitative researchers to access a targeted population and focus on a particular issue in order to seek an in-depth understanding of specific phenomena. Thus, qualitative studies target a sample that is rich in information (Patton 2007), as such only people who could enrich the study are invited. The informants who have a rich knowledge of the phenomenon under study are likely to provide an understanding of it (Gentles et al. 2015). My aim in this thesis is to explore the lived experience of pelvic organ prolapse from the perspectives of Saudi women who are around the age of menopause. Because this is a qualitative study, describing the process of sampling in detail is essential in order to ensure credibility and coherence.

Savin-Baden and Howell-Major (2013) reported that there are three common sampling approaches adopted in qualitative research: snowballing technique,

convenience sampling, and purposive sampling. Sampling using snowballing technique depends on participants' referrals to access other potential participants in order to complete the sampling procedure. This approach did not suite the current research as the topic under investigation is culturally sensitive and it was assumed that the target population would be or prefer to be hidden. In convenience sampling, the researcher recruit's participants from a population that is conveniently available. Convenience sampling was also not adopted for this research as it would negatively affect the attempts to generalise the findings of the research that results from the increased probability of selection bias and sampling errors (Etikan 2016)

In purposive sampling, the researcher determines who will best provide insight into the phenomenon under investigation. Purposive sampling has been adopted in this study because it adheres to the epistemological and ontological stances of the researcher i.e., there is no single objective reality about a phenomenon rather multiple subjective realities that can only be obtained from those who experience that phenomenon. This is because the principles of purposive sampling are about choosing participants who acquire a knowledge that will respectively help the researcher to obtain rich data related to the phenomenon of interest, choosing expert participants related to the topic of interest and their willingness to participate (Palinkas et al. 2015). Additionally, those expert and knowledgeable participants will be able to share their experiences and express their opinions regarding the research topic (Creswell et al. 2011). Palinkas et al. (2015) stated that purposive sampling is one of the most commonly used sampling methods in qualitative research.

# 5.2.1.1.Sample size

IPA utilises a small number of participants that are carefully situated and purposively selected to explicate how a particular experiential phenomenon is understood from the perspectives of particular people within a particular context in order to illuminate more general laws of human behaviour (Smith 2012). The sample in IPA should be homogeneous (Smith 2012); this is in order to ensure that the topic is of personal significance to participants, and it also permits the researcher to capture detail on a specific group of individuals who have experienced a particular phenomenon. This is achieved through the idiographic component of IPA that seeks small sample sizes so as to conduct intensive case by case micro level analysis so that each individual case has a locatable voice within the study. It was planned in this study to include 8-10 Saudi women experiencing the symptoms of pelvic organ prolapse in order to develop case by case generalisation, and permit each woman included in the study to be given a defined identity. Such sample size is acceptable in a wide range of qualitative research including thematic analysis.

# 5.2.1.2. Inclusion and exclusion criteria

The choice of IPA guided the study design and process, IPA and phenomenological studies in general tend to involve small samples that are carefully and purposively selected where participants share a common experience (Smith 2012). Moreover, IPA design requires homogenous samples, hence the findings are contextualised within the defined sample. Purposive sampling strategies employed for this research were as the following: women were included if they were around the age of menopause and experiencing the symptoms of pelvic organ prolapse. Due to the link of the condition to sexual behaviour and intimacy, it was decided that only married women would be included in the study in order to adhere to the cultural sensitivity. It was decided first that women who have not sought professional support to manage the condition would be included from the community. This is because, given the anecdotal evidence about the response of women to prolapse in Saudi Arabia, it was assumed that using referral chain sampling strategy or snowballing technique might be inappropriate and pose further challenges as these women are rarely seen seeking professional support in Saudi Arabia. Moreover, qualitative research seeks to explore phenomenon in natural settings, I wanted to understand what happens to the daily lives of women after developing the symptoms of pelvic organ prolapse, and how do they make sense of it in their natural settings surrounded by the world they live in. The inclusion criteria were later altered to also include women who have sought healthcare support for managing the condition as the strategy to included women from the community failed to recruit participants.

# 5.2.2. Recruitment

Research participant recruitment has been defined as the process of identifying potential participants, providing them with information about the study, obtaining their formal consent to take part in the study, and successfully including them in the research (Berger et al. 2009). Recruiting participants successfully is pivotal to exploring the research question because insufficient recruitment threatens the validity of the study (Daly et al. 2019). Researchers often face a variety of challenges during recruitment, most frequently mentioned, being related to time constraints (Verma et al. 2016). Being a qualitative research, the methodological approach adopted for this study requires recruiting participants who represent the richest source of information relevant to the phenomenon under investigation.

Prolapse is a sensitive topic and accessing participants with traditional recruitment methods for sensitive research has been reported to be difficult and ineffective at times because of their social and physical locations, vulnerability, or hidden nature (Ellard-Gray et al. 2015). Hence, it is paramount for the researcher to understand and define the sample of interest and the appropriate way to approach them because failure to do so could lead to unrepresentative results (Records and Rice 2006). Despite the target sample has been well defined and described as above, determining the most effective recruitment strategy for sensitive research may still be challenging. Therefore, the plan of recruitment was to access participants through three streams all of which are discussed below.

#### 5.2.2.1. Methods of recruitment

The perspectives of women who had not sought professional support were sought initially; therefore, it was deemed suitable to recruit participants from public places and the general population. Previous studies that looked at the experience of women with prolapse recruited participants through referral systems (Shrestha et al. 2014; Gjerde 2017); participants that met their inclusion criteria were referred to researchers by physicians.

Multiple streams for recruitment were ultimately used with ethical approval from Cardiff university. Initially, an advertisement picture that included the main symptoms of prolapse in addition to my contact details was distributed (see appendix C). The information was typed in Classical Arabic, which is commonly used in formal communication and in documents. The decision to use Classical Arabic in the flyer was taken because it was considered that this would gain womens' trust. Moreover, given the geographical size and area of Saudi Arabia, the lay Arabic language people speak varies from one province to another, one word in lay Arabic in the western province could have a totally different meaning in the Northern province. Hence, it was deemed that using Classical Arabic language in the recruitment flyer would be more broadly understood by women who are originally from different provinces of Saudi Arabia. Participants were initially recruited through two streams: flyers distributed in women gathering areas and social media platforms. These two methods however failed to recruit participants.

### 5.2.2.2.Recruitment stream 1

Flyers have been used in a variety of research projects and are useful to gain the attention of potential participants (Frandsen et al. 2016); nevertheless, they may not motivate them to take part in the study. This has been demonstrated in a number of studies that have recommended placing flyers in multiple places accessible by the population of interest. Flyers were placed in six different locations across the city of Jeddah which were carefully chosen because of their popularity among women, location and ease of access. Originally, the administration offices in 13 locations were approached to place flyers in their facilities but only six approved. The chosen locations are only accessible by women in order to adhere to cultural sensitivity. No participant was recruited through this method.

# 5.2.2.3.Recruitment stream 2

It has been stated that social media is emerging as promising method for identifying and recruiting potential participants for research purposes; hence researchers are exploring ways in which social media can be utilised for research (Rife et al. 2016).

Initially, this study aimed to explore the experience of Saudi women with POP who did not seek professional support to manage the condition. This required accessing the hard-to-reach target population through public streams. Hence, twitter was used as a method for recruitment. No participant was recruited through this method, but to ensure transparency, the process of twitter-based recruitment is outlined below.

# 5.2.3. The process of Twitter based recruitment

## 5.2.3.1.Twitter account

I have used my personal account for recruiting participants. It was a semiprofessional account, in which I posted or retweeted healthcare and research related information. My personal details were originally added in the biography section such as my professional background, my position as an academic at Umm Al-Qura University (UQU), and my current position as a PhD researcher at Cardiff University. Adding these details was deemed essential to gain the trust of women who will potentially see the research recruitment tweet. To further maintain integrity, I have reviewed my Twitter profile page and deleted any Tweets that did not seem professional or were considered personal.

#### 5.2.3.2. Recruitment tweet

The recruitment tweet was in the form of an image with content and design similar to the flyer that was distributed in the above-mentioned locations, but with an adjusted size appropriate to be visible on Twitter page without the need to click on the image to see the content.

# 5.2.3.3. Promoting tweet

The image was first posted to my account with a note to my followers "kindly, retweet". Secondly, a total of 43 Twitter users were either mentioned or contacted by direct messages to retweet the post. Twitter ad service was also used to ensure that the tweet is viewed by the population of interest. It is a paid service that enables the user to select the audience of the tweet according to gender, location, and age group. It also enables the user to select the timing of the tweet and whether the user wants the tweet to be re-viewed by users who already viewed it once. Initially the user sets a budget and decides how much maximum he or she would like to spend on the ad or "campaign" per day. The transaction is often approved at the end of the campaign. The charge is based on the total number of users who viewed or engaged with the tweet; therefore, it was important to ensure that the tweet is viewed by the population of interest. The tweet audience was selected as following,

I set a maximum budget to £460, and I have chosen the tweet to be viewed by women who are above 39 years old and living in Makkah region, the western province of Saudi Arabia.

# 5.2.3.4. Results of Twitter based recruitment

Recruitment through twitter took place between 22 June and 7 August 2019. From the 22<sup>nd</sup> of June to the 2<sup>nd</sup> of July recruitment was limited to mentioning specific users to retweet the recruitment posts. Promoting the tweet using Twitter ad service was initiated after no response through mentioning method.

Table 2: Response of followers on Twitter

Number of followers	Total responses
177	3

Table 3: Response yielded through mentioning method

User category	Number contacted	Responses
Physiotherapy professional bodies	8	0
Women's health professional bodies	6	0
Physician	10	2
Physiotherapists	15	0

Table 4: Responses yielded through Twitter ad service

Week	Campaign	Viewing	Likes	Retweets	Comments	Total spent
1	Awareness	23,449	12	4	0	£50
2	Engagement	2142	2	1	0	£24
3	Awareness	8610	4	1	0	£30
4	Awareness	35,469	22	9	0	£93
5						

Table 4 demonstrates that the tweet had been viewed by a total of 69,670 twitter users who met the criteria that were selected, women above the age of 39 and are living in the western province of Saudi Arabia. Nine women contacted me through direct messaging in Twitter, and five contacted me on the research phone number that was documented in the recruitment image; nevertheless, none of them agreed to take part in the study.

# 5.2.3.5.Polling data from Twitter

Twitter ad service and audience were selected similarly to the audience of the recruitment tweet, the polling tweet was the following:

"Pelvic pressure or bearing down.

Leg fatigue & low back pain.

Stress incontinence or difficulty passing urine.

Bowel problems and constipation.

Painful intercourse

1 in 12 women around the age of menopause experience these symptoms, are you one of them?"

The answer options were:

- Yes, and I have sought professional support.
- Yes, its normal and does not require treatment.
- Yes, but I am hesitant and embarrassed to seek professional support."

The tweet was viewed by 40,533 users, and only 993 users voted using the poll. Only 25% have sought professional support for managing the condition, nearly half of the respondents were hesitant and embarrassed to seek professional support, and 33% considered it normal and that it did not require treatment. Further details on this method of recruitment are presented in chapter (9).

# 5.2.3.6.Adding recruitment stream 3

The decision of adding a third stream of recruitment was taken after the failure of both streams presented above in recruiting any participant. There are four hospitals in the western province of Saudi that are equipped urogynaecology clinics. Access to two hospitals was limited due to gatekeepers' restrictions, and the third hospital as at the time of the study was under maintenance and was evacuated. Hence access was obtained to one hospital.

# **5.3.** Access negotiation

An agreement was reached that participants could be recruited from the single hospital setting. I have gained approval from one of the large hospitals in the city of Jeddah to access participants from the obstetric and urogynaecology clinic. Access was negotiated with the team leader who had previously contributed to the early stages of planning this research project. Prior to gaining approval to access this facility, staff were given a short presentation to introduce the project to the urogynaecology team highlighting the aims and objectives and the target group for recruitment.

#### **5.4.Obtaining ethical approval**

The research governance process was ensured by gaining ethical approval from Cardiff University, the School of Healthcare Sciences (HCARE) by submitting a research proposal to be scientifically reviewed. The final review report was granted in September 2019 (appendix A). I encountered difficulty in recruiting participants from social media and the community alone, therefore I had to think of an alternative way that would guarantee successful recruitment. Hence, national ethical approval was also obtained from a specialist hospital in Saudi Arabia (Appendix B). This was followed by adjusting the research proposal and gaining ethical approval from Cardiff university once again.

## 5.5. The process of recruiting and inviting participants

The following practicalities were considered to support participants' recruitment and invitation within healthcare settings: The urogynaecology clinic runs essentially throughout the week, but as I was initially collecting data during the summer vacation, the clinic ran only every Tuesday and Wednesday. I attended the clinic on a weekly basis for three months to recruit participants and there was a private room designated for me by the department where I would wait for potential participants to be referred to me. The plan was as the following: after the clinic triage nurse ensure that the patient meet the inclusion criteria, she would inform the patient briefly about the ongoing research and ask her if she would like to take part in the study. If the patient agrees to do so, she would ask her to meet me in the designated private room so I could explain the study and provide her with the participants information sheet and the consent form (see appendix E and F). As per the data protection act (DPA) (DPA 2018), a transparent process was applied in this study through being open, clear and honest with the participants about how their data would be used. The motive for providing participants with information about the current research was to allow them to decide whether to participate in the study or not. I have used DPA regulations, which is a UK data protection regulation, in accordance with best practices and Cardiff University's regulations.

Each participant was given time to read the participant's information sheet and the consent form, consider participation, ask any questions and then respond. Women were given the option to take the time they need to respond to the invitation to participate in the study. Alternatively, they were also offered to respond right away as patients usually wait for almost 1 to 2 hours before being seen by the physician. In order to ensure ethical practice, I went through both forms with participants and ensure they understand everything clearly and correctly and seek their verbal and signed approval.

I have emphasised that participation was voluntary and that all participants had the right to refuse to participate in the study at any time. Furthermore, I have sought informed consent from the participants to clarify that they understand that participation in the study was voluntary, and that I as a researcher was allowed to use anonymised quotes for the study. Each patient was informed that participation

is confidential and would not affect the care provided by the hospital. They were also informed that they can withdraw their consent and use of data at any time, my professional contact details were provided to each patient in case they want to withdraw from the study.

#### 5.6.Method of data collection

### 5.6.1. Face to face interviews

It is argued that interviews 'describe, explain and explore' participants' experiences from their perspectives (Kvale 1996). In-depth, face-to-face interview has been used as a method for data collection to gain an understanding of the lived experience of pelvic organ prolapse of Saudi women around the age of menopause.

The use of interviews was particularly relevant to this research because it aimed to generate an understanding of women's experiences of prolapse. Using interviews was suitable because it enabled an exploration of the participants' views regarding the phenomenon under investigation. Moreover, in-depth interviews are relevant for researchers who are interested in exploring participants' perspectives of events, and in understand how events, actions, and meanings are connected in the context of participants' lives (Creswell 2006).

According to Galvin and Holloway (2015), face-to-face interviews allows the researcher to observe the non-verbal expression of feelings (through body language and eye contact) that further helps in interpretating what had been said during the interview. Indeed, it facilitated the interpretation of participants emotions during data collection and analysis (Galvin and Holloway 2015).

The interview questions were generated in line with IPA framework and discussion with experts in the field from Cardiff University. They were designed to elicit women's experience and understanding. The interview guide included open-ended questions with probes to encourage expansion of ideas and get more depth in the participants' stories of prolapse. The interviews were led by participants' responses but were focused on covering three key areas:

• How pelvic organ prolapse broadly affects the lives of women

- Women's sense making and understanding of the condition
- Exploring women's responses to the condition and their healthcare seeking behaviours

The interview questions were designed in a non-chronological order, funnelling from general to sensitive questions (Kvale 1996). The interview began with how women first identified the symptoms of pelvic organ prolapse, their knowledge and response to it, and finishing with healthcare experience. As indicated earlier, prolapse affects sexual health; therefore, participants were also asked about the implication of prolapse on their sexual life and spousal response but only after building rapport and when it was considered that they were willing to talk freely about their sexual life. Asking such direct questions may not exactly fit with IPA interview framework but based on the sensitivity of sexual health related topics in Saudi Arabia, I felt that this is probably not something that women would feel able to discuss unless given explicit permission.

#### 5.6.2. Interview process

All study participants chose to be interviewed on the day of recruitment. After meeting each participant, for all the interviews, on the day of the interview, I welcomed the participants and thanked them for initially considering participation. It has been previously indicated that a good communication is essential to qualitative studies (Bartkowiak 2012). According to Churches and Terry (2007), this will help in creating a relationship or state of having trust and mutual responsiveness between researcher and participants. Such productive communication should start with trust and understanding. Molden and Winterheld (2013) believed that this understanding and trust for participants so they would not be sceptical and suspicious about the researcher and the study. Therefore, it is paramount for the researcher to develop a good relationship with study participants. Building good interpersonal relations between researcher and participant is an important aspect of qualitative research that needs to be considered particularly when the researcher engages in interviews and observations as it will aid in generating rich data (Guillemin and Heggen 2009).

I started an informal conversation with the potential participant about their day. I handed them the information sheet and consent form and went through them both before gaining their consent to participate in the study. Women who had agreed to participate, the consent written in the Arabic language had been obtained prior to the interviews, it describes the study and its objectives, the potential risks and benefits to participants, as well as the data management process to maintain confidentiality. The consent form informs participants about the option of withdrawing from the study at any time without compromising their healthcare.

Before the interview started and the digital audio recording took place, I talked with the participant about general topics not related to her condition and offered refreshments and coffee to the participants, creating a comfortable environment for a conversation in order to break the ice and establish a trustful relationship. Melville and Hincks (2016) believe that establishing rapport is the first step in conducting the actual interview. Rapport is defined as the establishment of trusting relationship between researcher and participant. Building rapport can help the researcher to gain access to research setting and also motivate participants to agree to an interview (Agar 1996). It also helps in opening up conversational space (Owens 2006). By having a good rapport with participants, researcher may be able to obtain better information and data access due to the trust and understanding built as a result from the good relationship between both of them. This is specifically important because the topic under investigation is sensitive in the context of Saudi Arabia, and without rapport building, women may not be prompted to share private information about their experience.

Women were given time to talk by scheduling a suitable interviewing time, rest break, and providing a safe and private environment. Gardner et al. (2005) emphasised the importance of informing the interviewees from the start of the interview about the timing as to make them aware of how much information to share. Nevertheless, it is suggested that participants in sensitive interviews should not be rushed, and the researcher is advised to allow time to develop rapport, participants are able to cry, take a break or move between topics as need be (Melville and Hincks 2016). Participants also need to feel that they can express their feelings during the interview without being constrained by time (Cowles 1988). The interviews lasted between 23 minutes to 35 minutes and included pauses because some women were hesitant to speak about their condition despite their approval to participate and the build rapport. The interviews' private setting at the hospital helped the recordings to be clear with minimal noise and distractions and maintained confidentiality. During the interviews an open atmosphere of trust and understanding was encouraged to enable participants to feel free to share their experiences and feelings.

Women's reactions (verbal and non-verbal) during the interview and the uncovered issues were captured by the use of reflective field notes. Field notes were made immediately after each interview to reflect on the process and my experiences. I was aware of the bodily aspect or language of the interview particularly when discussing difficult events that might cause distress when revisiting the experience. All these were noted and helped me to be aware of the impact of the interview not only on them, but also me. Keeping a reflective diary is good practice for qualitative researchers (Ortlipp 2008). Thus, keeping a reflective diary will help me to maintain reflexivity throughout the research process: data collection and analysis, and other stages of the research in general in order to minimise any possibility of bias. This helps me as a researcher to acknowledges that I am a part of the social world of phenomena I am studying, where I am a young Saudi woman sharing the world with study participants "Saudi women around the age of menopause", and I also have educational knowledge about prolapse compared to their experiential knowledge.

## **5.7.Practicalities**

Records containing personal data, such as participants' names, addresses, and telephone numbers were securely held to prevent unauthorised or unlawful access and accidental loss or damage, in order to comply with the Data Protection Act (DPA) (DPA 2018). During data analysis, publication, and presentation, the participants were given different names to protect their identities, to prevent being recognised by their peers and preserve anonymity.

All manual files and recordings were locked in a secure cabinet at the assigned hospital in Saudi Arabia, with controlled access by the researcher until transcribed

and verified. and were then destroyed before return to Cardiff. In addition, I have used a personal laptop computer to save the audio-recordings, transcripts and any documents related to the study's participants. This laptop was password protected and was only used and accessed by me. An encrypted area was created on the laptop where all the data were securely stored (Data Protection Act, 1998). Following Cardiff University guidelines, electronic data and paper documentation are securely stored at Cardiff University until destruction occurs at the end of the holding period, which is 15 years from the end of the project. All electronic information was encrypted and securely saved in the Cardiff University H drive server and locked by a password. The interviews were recorded using an MP3 digital recorder and a lapel microphone and were downloaded directly onto my personal laptop hard drive.

## **5.8.** Chapter summary

This chapter has provided an overview of the study process and logistics. It has highlighted the practical difficulties encountered during sampling and recruitment, which further highlighted the sensitivity of the condition in Saudi Arabia. It was concluded that recruiting participants for sensitive research through public streams and social media might not currently be suitable as a method in Saudi Arabia. A sufficient number of participants were finally recruited from one hospital and data collected using semi-structured interviews.

# 6. Chapter Six: Data Management

## **6.1.Introduction**

The aim of this chapter is to demonstrate the process undertaken to manage the study data and the steps of data analysis. IPA as a methodological approach guided the initial processes of this study, in terms of sampling strategy and data collection method. However, an IPA analysis was found to be problematic and a revision to the analysis methodology had to be considered. Reflexive thematic analysis was utilised to analyse the data, the results of which are presented as the findings in chapter (7).

### 6.2. Data translation and management

Recruitment, data collection, and transcription of the study data took place over a year. Interviews were only transcribed after the completion of data collection in order to avoid any thoughts that may arise and affect the next interview process and perhaps distract me from focusing on the next participant's story. Interviews in essence can be transcribed verbatim or non-verbatim. The verbatim transcription is a word for word transcription, and it includes coughs, laughs, errors in spoken words, sentence structure problems and incomplete sentences. Conversely, the non-verbatim transcription "also known as clean verbatim" does not record stutters, filler speech such as "Umm" or "Uh", errors in spoken words or non-verbal sounds such as coughing and laughing (Halcomb and Davidson 2006). Interview data for this study were transcribed in Arabic because the interviews were conducted in the Arabic language and then translated verbatim into English after the completion of data collection. The process of translating each interview took around one week. The interview transcripts indicated hesitancies, pauses, laughter, and some emotional sounds.

Halcomb and Davidson (2006) claimed that verbatim transcription is a time consuming and complicated process that may include technical dilemmas such as misinterpretation of the generated data, cultural differences, and language errors. In the current research, I have attempted to control this issue through note taking

during all the interviews. This enabled me to capture thoughts and interpretations of the data when listening to the recorded interviews.

Primarily, due to resource limitations, I personally undertook the translation of the interview data. The translation process was lengthy and challenging, especially looking for words in English to reflect the complex meaning of the original Arabic. Every effort was made to translate the Arabic idioms used by women into appropriate English language. The support of an Arabic speaking Saudi colleague who has a master's degree in English language was sought when there was any difficulty encountered during translation.

To achieve familiarity and comprehension, I thoroughly read the transcribed documents multiple times, repeatedly listened to the recorded interviews, and reread the transcribed texts as necessary for data analysis. It was anticipated that this method will help in maintaining the accuracy of what the women said and reduce the impact of researcher bias during translation.

## 6.3.Data analysis

The IPA framework was initially used for analysing the study data. Qualitative data management software packages were not used because they are not suitable for IPA, where it is recommended by Smith (2012) to use a hard copy of the transcript in data analysis. IPA has a flexible set of stages where the analysis moves from the transcripts to a table of themes and finally to a table of superordinate themes. These stages move from individual to shared experiences and from the descriptive to the interpretive level (Smith 2012).

### 6.3.1. Process of IPA

The following steps are proposed by Smith et al. (2009) where each interview is treated as a single case study:

- 1. Familiarising with text and getting close to the data through reading and re-reading the transcript and listening to the interview recording.
- 2. Making notes on the transcript document. These notes are on three levels: descriptive notes with focus on the contents, linguistic comments exploring the

use of language by the participant; and conceptual comments that engage with the data at a more integrated conceptual level.

- 3. Each transcript is treated as a single case and analysed line by line to identify the emergent themes. The themes are then connected and clustered to detect patterns in each participant's transcript.
- 4. Moving away from the transcript and searching for patterns across transcripts and laying all the themes on a large surface and reviewing them.
- 5. Shift from idiographic phase to higher level of conceptual analysis and shared experience.
- 6. Identifying patterns and connections between the emergent themes. This involves abstraction, putting similar themes together and naming the theme; polarization, identifying relationships and differences (negatives and positives); contextualisation, developing the contextual and narrative themes; and numeration, noting the frequency with which a theme is mentioned, which could indicate its relative importance (Smith et al. 2009).

# 6.3.2. Changing to reflexive thematic analysis

The IPA approach to analysis was not facilitating the clear identification of findings from the data. This was primarily because linguistic analysis is a critical component of IPA (Smith 2012). Finding the exact meaning of some words the women used was not fully achievable, possibly because women spoke about hidden and sensitive issues and their ways of expressing their feelings was radically different across women, and close and personal to each woman. During the initial analysis, particularly the language analysis, I felt that I was analysing my own words rather the participants words that reflected their personal sensitive experiences. Further details or provided in chapter (9).

An alternative method of analysis was sought to analyse the data collected for the current study because of the issues which became apparent during the initial attempts. Reflexive thematic analysis (RTA), proposed by Braun and Clarke (2006), was considered to be an appropriate alternative. Because this study was

guided from the outset by the IPA framework, the change in the method of analysis called for a flexible analytical approach. RTA was deemed suitable for analysis of the dataset because it is flexible in its approach and can be considered appropriate with wide range of epistemological stances.

Originally the data collected for this study was to be analysed using IPA, but subsequent to initial attempts RTA was used. With this in mind, congruent or supportive studies for this change were sought, but there is paucity in evidence regarding this issue, supportive or otherwise. There is one study by Speirs and Riley (2019) that compared the use of IPA and TA on the same dataset to compare the findings from two analyses and achieve analytical pluralism. Although Speirs and Riley' s (2019) study had no similarities with this study in relation to the subject, the comparison of the two forms of analysis supported the substitution of one for the other by demonstrating that the findings were congruent whichever analysis was presented. This study was informative in terms of the possibility for data collected for an IPA study to be analysed using TA, further supporting my decision.

The process of analysis is presented below, but the analysis was conducted on idiographic or individual level (see appendix G) then moved to shared level (see chapter 7). It was acknowledged that the initial attempts to conduct an IPA analysis has placed me very close to my data, thereby detaching from the data at this stage seemed impossible. Additionally, it was critical to ensure that the voice of each woman is still heard because of the differences in their experience. Doing case by case analysis will demonstrate how the shared understanding was reached from each woman's unique experience.

#### **6.4.Reflexive thematic analysis**

Thematic analysis (TA) is an approach of qualitative data analysis that has been proposed by Braun and Clarke (2006). TA has been widely used in literature, yet it is argued that the use of the approach is often based upon the interpretations of the researchers (Byrne 2021). Braun and Clarke (2019) have acknowledged the limitations in their approach proposed in 2006 and attempted to correct the misconceptions in their article published in 2019 through differentiating between

three principal approaches of TA: coding reliability TA, codebook approach to TA, and reflexive thematic analysis (Braun and Clarke 2019).

Reflexive thematic analysis (RTA) is an interpretative approach of TA, it facilitates the identification and analysis of patterns and themes in the data (Braun and Clarke 2019). RTA goes beyond measuring frequency of codes and extends to understand the complexity of meanings in the data through interpretation and reflexivity opposed to other TA approaches that determine themes according to the number of times the codes were repeated in the dada set.

# 6.4.1. Justifying the choice of RTA

## 6.4.1.1.Theoretically flexible approach to qualitative data analysis

Braun and Clarke (2006) indicated that TA is a theoretically flexible approach, but this does not mean that it should be theoretically uninformed. Despite the flexibility it offers in terms of the epistemological and ontological perspectives, RTA as a pure qualitative approach may only be used under an appropriate qualitative paradigm (Braun and Clarke 2020). Thus, RTA was suitable to address the study aims and objectives given that this study was always conducted under an interpretivist paradigm.

RTA considers qualitative research to be about meaning making, and these meanings are believed to be bound to context (Braun and Clarke 2021). In addition, qualitative data analysis is about telling interpretated stories; hence, the final RTA should be a result of deep and prolonged immersion in the data.

# 6.4.1.2. Acknowledge active role of researcher in knowledge production

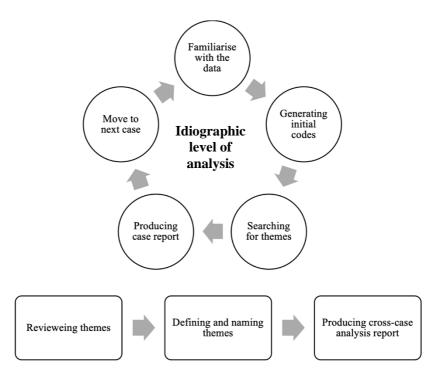
The researcher's subjectivity is understood as a resource in RTA (Braun and Clarke 2019). The process of analysis in RTA will represent my interpretations of patterns of meanings across the data set. In essence, Byrne (2021) stated that RTA is reflection of researcher's interpretative analysis. Similar to IPA, the codes and themes produced during the analysis may not be reproduceable by another researcher. The analysis is a result of my full engagement with the data and the analytical process.

# 6.4.1.3. Flexible analytical process

The process of analysis in RTA is not rigid, it is rather flexible and evolves throughout the analysis (Campbell et al. 2021). This facilitates familiarity with data and allows for interpretation of further new patterns of meanings. This quality of RTA will accept my closeness to data because after attempting IPA I am no longer able to approach the data from a naïve perspective. The researcher is encouraged, when using RTA, to approach analysis while embracing reflexivity, subjectivity, and creativity as important elements in knowledge production. Thus, RTA allows me to analyse the data on an idiographic level followed by shared or cross-case level.

## 6.4.2. Phases of reflexive thematic analysis

The steps of thematic analysis as proposed by Braun and Clarke (2006) were undertaken with the translated interview transcripts. Because of the flexibility of TA as an analytical approach and my closeness to study data at this stage, each transcript was treated as a single case study and was thematically analysed before moving to the next participant. The steps of thematic analysis undertaken for this study are presented below:



**Cross-case analysis** 

Figure 2: Phases of reflexive thematic analysis

# 1. Familiarising with the data

At this stage of the analysis, I was already familiar with the data. However, I tried to approach each transcript with fresh eyes and actively listened to the recording before moving to the next step. This provided me an opportunity, unburdened by tasks such as note taking, to recall gestures and mannerisms that may or may not have been previously documented in the reflexive diary.

# 2. Generating initial codes

By this time, I had already gained an understanding of what was contained within the interview data and had considered what might be relevant to the study. However, these thoughts were suspended as much as possible because in thematic analysis, codes are perceived as the fundamental building blocks of what will later become themes (Byrne 2021). Coding was done systematically line by line and each interview was given the same attention. Parts that were relevant to the research were then coded (Braun and Clarke, 2006). The method for developing the codes is dependent upon whether the themes are data driven or theory driven. For this study, initial codes were generated from the data. Codes represent an aspect of the data that appears relevant to the analysts and is the most basic form of the raw data which can be assessed in a meaningful way about the phenomenon (Boyatzis, 1998). Coding in this study was driven by data because the analysis process was inductive. Inductive analysis is dependent on the data and the codes generated are driven by the data and not pre-existing theories. The initial codes at this stage were largely descriptive in nature and close to what each participant said.

# 3. Generating themes

I began searching for themes after all the data in the transcript had been initially coded and the codes had been collated into a list. The codes were sorted and aligned into potential broad themes with all the data under each of the codes that had been grouped and then codes grouped into potential themes. Mind maps were made for the initial themes that were developed by grouping aligned codes together. This process helped draw relationships between codes and between themes and sub-themes within those. Some codes became themes, others became subthemes, and some were discarded.

# 4. Producing a case report

At this point, an idiographic or individual case report was produced for each transcript and a mind map of the participant's generated themes and subthemes was made. Because each participant's meaning making and interpretations of the world they live is important when approaching reality through an interpretivist paradigm, the themes generated from each transcript were at a latent level and this was achieved through interpretating the participant's narrative. After producing each case report, I moved to the next transcript and step 1 to 4 was repeated.

# 5. Reviewing themes (initiating cross-case analysis)

This step was undertaken after generating initial themes and producing case reports of all data sets. Before reviewing the generated themes, it was important to look for the shared themes through performing a cross-case analysis. Step three of thematic analysis was repeated at this point. The focus shifts from the interpretation of individual data items within the dataset, to the interpretation of aggregated meaning and meaningfulness across the dataset. The generated themes from each transcript were added to a table on Microsoft word including the pseudonyms given to participants and connections across the themes were looked for. To ease the identification of shared themes, a major mind map was made, all themes and subthemes generated from each transcript were written on white board and I started to look for connections across the themes and subthemes (see appendix I). Similar themes started to form categories. For example, all women spoke about healthcare but in different ways, some spoke about their past experiences and how they have affected their healthcare seeking behaviour, others have spoken about their experience of seeking support for prolapse and the treatment options offered whilst some indicated that they were disadvantaged by late access. Similar topics were grouped into one category so there were three categories in terms of healthcare support:

- Healthcare seeking behaviour
- medical treatment options available
- limitations in healthcare system.

Thus, after identifying the shared themes, these themes were refined to ensure that there was both internal homogeneity and external heterogeneity. Patton (1990) indicated that internal homogeneity means that the data within each theme are coherently meaningful, while external heterogeneity means that there should be a clear distinction between the generated themes. In refining the themes, I ensured that there was coherence of the data within each theme and there was a clear distinction between the themes. Some themes had to be broken up and some were merged. By the end of this phase a clear idea of how the various themes fitted together and the story each theme told about the data became apparent.

# 6. Defining and naming themes

In this phase there is further refining and defining of the themes. The themes are defined in terms of what they are about, relevance or importance and a determination made of the aspect of the data that the theme captures. The story told by each theme was analysed and woven into the overall story of the data to make

it coherent. The structure of each theme was refined to ensure that there was a flow to the structure. The names of the themes were reviewed in this phase to ensure that they were concise and that they gave the reader an idea of what the theme is about.

# 7. Producing cross-case analysis report

The final phase is producing the report. The report must be analytical and include vivid extracts from the data as examples. 'It should be consistent, coherent, logical and non-repetitive and form an interesting account of the story the data tells' (Braun and Clarke, 2006). Extracts were provided within the report that demonstrated the presence of the themes in the data in very simple terms. The write-up went beyond just reproducing extracts by being analytical.

## 6.5. Chapter summary

IPA was initially chosen as a methodological approach and attempts to analyse data using IPA were commenced. Nevertheless, IPA did not work for this study because of the linguistic analysis component, which was challenging because of the translation from the original text and the hidden topic under investigation being expressed with much shared understanding. As an alternative, RTA was utilised to analyse the data because of the flexibility RTA allows in terms of theory and analysis. In addition, it also accepts my role as a researcher and producing knowledge; thus, is aligned with my epistemological stance.

## 7. Chapter Seven: Study Findings

## 7.1.Introduction

This chapter seeks to present the study findings which focus on highlighting the unique and shared experiences of married Saudi women who are around the age of menopause and suffering from pelvic organ prolapse. The thesis aim was to explore the lived experience of pelvic organ prolapse of Saudi women around the age of menopause. Prolapse is a health condition requiring healthcare intervention, this research is based on the idea that women with prolapse in Saudi Arabia avoid or delay seeking professional support that affects physiotherapy service delivery to these women, and that culture may be informing their experience.

The objectives of the study were to:

- Explore the impact of culture in Saudi Arabia in shaping the experience of pelvic organ prolapse.
- Be respectful of the potential individuality and subjectivity of the experience due to the sensitivity and hidden nature of prolapse in Saudi Arabia.
- Provide recommendations for healthcare service provision based on the experience of women with prolapse through disseminating information so that other healthcare professionals can better understand women's experiences.

Reflexive thematic analysis (RTA) undertaken to analyse study data led to the development of five key themes. The main themes generated as described in the previous chapter (chapter six) and linked to the aims were as follows:

- Conceptualisation of prolapse
- Social support provided by family
- The physical implications of prolapse and impact on marital relationship
- Healthcare seeking behaviour of women with prolapse and health service limitations
- The role of Saudi Arabian culture in shaping women's experience of prolapse.

Each of the themes consisted of subthemes, these are presented in the table below.

Generated themes	Subthemes <ul> <li>a) Lack of knowledge</li> <li>b) Attributing causes to prolapse</li> <li>c)Adapting to the condition</li> </ul>		
1. Conceptualisation of prolapse			
2.Social support provided by family	<ul><li>a) Disclosing illness</li><li>b) Receiving support</li></ul>		
3. Prolapse and marital relationship	<ul> <li>a) Physical impact of prolapse and altered body image perceptions</li> <li>c) Implications on intimate life</li> <li>d) Response of husband</li> <li>e) Meaning of sex</li> </ul>		
4. Healthcare seeking behaviour	<ul> <li>a) Factors affecting healthcare seeking behaviour</li> <li>b) Limitations in the healthcare system</li> </ul>		
5. Role of Saudi culture in shaping the experience of prolapse	<ul> <li>a) Family dynamics and women's relationships</li> <li>b) Gender ideologies and roles of women</li> <li>c) Cultural beliefs informing the sensitivity of prolapse</li> <li>d) The perspectives of Islamic religion</li> </ul>		

Table 5: Generated themes and subthemes

The RTA of the study data was undertaken following attempts of analysis using IPA. As discussed previously in chapter (3) and chapter (6), the IPA approach was at first chosen as a methodological approach to address study aims and objectives. However, at the stage of data analysis, it appeared that IPA was not suitable to achieve an understanding of the experiences of Saudi women with prolapse; therefore, the analytical approach was changed to RTA.

Due to the idiographic commitment of IPA, I as a researcher was immersed in participants narratives and their personal experiences which have still been captured in the findings chapter by giving biographical context to each of the participants experiences. RTA has moved the analysis beyond their individual experiences and aimed to capture what is shared in terms of the experience of prolapse across the study participants. The five generated themes were shared across the participants, and this was identified by constantly engaging with their narratives. This chapter will present those findings and will illustrate how the participants' narratives resulted in generating the themes.

One of the rationales for choosing IPA as an approach to analysis was its idiographic commitment that ensures that the voices of women are heard, and that each woman has a locatable voice in the findings following the interpretation of the data. Although the analytical approach was changed to RTA, this study is about the lived experience of a personal phenomenon. Therefore, it was deemed appropriate to present the findings through first providing a descriptive biography of each of the study participants in order to set the scene for the reader about the stories of these women and to illustrate how the shared understanding was developed from their uniquely embodied particular experiences, further ensuring that their voices are heard.

#### 7.2.Participants' descriptive summaries

A total of eight participants were included in this study. Each of the women had a different story and experienced prolapse differently. Identifying the shared experience required immersion in the data and the structured approach (Braun and Clarke 2006) is outlined in chapter (6). The interview extracts are presented as evidence to support the theme and are provided with the pseudonyms of each participant. This is because the interpretation of participants' narratives was relevant to their personal stories and experience of prolapse.

The following table presents brief information about the eight women who participated in this study. Biographical and clinical details of each participant are presented in a chronological order according to the date they were interviewed in.

Name	Age	History of prolapse	Interventions if any	Interview length
Nabeela	59	Symptoms started 18 months ago, sought support after one year of experiencing symptoms	None	34 minutes
Lilly	49	Symptoms started 2 years ago, she got pregnant and had a miscarriage, then sought support afterwards.	None	35 minutes
Salwa	60	Symptoms started 1 year ago, sought support 6 months after.	None	25 minutes
Dina	54	Symptoms started 4 years ago, and this was her first time seeking healthcare support.	None	35 minutes
Aziza	62	Symptoms started 6 months ago, sough support after four months	None	23 minutes
Mai	51	Symptoms started 5 years ago during pregnancy, sought support immediately but got pregnant again.	None	33 minutes
Zainab	62	Symptoms started 6 years ago, sought support few months later in the UK	Pessary	28 minutes
Lujain	61	Symptoms started two years ago and started seeking support almost 18 months after.	None	23 minutes

# Table 6: Study participants information

## 7.2.1. Nabeela

Nabeela is a 58 years old woman, she is married and has five children. All of her children are married except her youngest son who lives with her and her husband. Nabeela is a housewife who does not have help at home so she often does all her housework chores by herself and would ask her daughters for help occasionally.

Nabeela's experience with prolapse started approximately two years ago. She complains of a descended uterus, difficulty in passing urine, pain, and occasional bleeding. Nabeela also had other health problems such as knee osteoarthritis that impacted her experience.

Nabeela was my first participant. She was welcoming and happy to take part in the research. During the interview, she spoke about her understanding of prolapse and what she has done this far to manage her condition, until she sought healthcare support at the hospital. She discussed how her mother also had experienced a prolapse and spoke about this while reflecting on the differences and similarities between them in terms of their experiences of prolapse as well as the cultural differences between her generation and her mother's generation.

## 7.2.2. Lilly

Lilly is a 49 years old woman, she was the youngest participant in this study. Lilly is a housewife, has 8 children, and has had 3 miscarriages. She is not an outgoing lady as she spends most of her time at home.

Lilly's symptoms of uterine prolapse started two years ago as a sense of heaviness and pain, there were also symptoms of UI. Lilly got pregnant few months after developing prolapse and had miscarriage, her symptoms got worse after undergoing dilation and curettage. She sought support after, and the doctor identified a benign uterine fibroid that has been managed but she gave no information about the method of management. After this, Lilly sought support again to manage her prolapse symptoms, and while she waited to be seen by doctor, her condition further regressed as her symptoms got much worse and affected her life greatly. Lilly spoke about her experience with healthcare and how she felt at times that she was disadvantaged by it. During the interview Lilly spoke a lot about some life events that she thought women undergo and causes them to have uterine prolapse. Lilly wasn't that only one in her family who had uterine prolapse, she disclosed that all her sisters also have the same problem. Her experiences reflected certain gender related ideologies and her religious beliefs.

## 7.2.3. Salwa

Salwa is in her early sixties. She is married and has five children. Salwa was a medical student but after getting married and having children she decided to give up her education, did not qualify, and became a housewife.

Two of Salwa's children are healthcare professionals at the university hospital; her daughter is a dentist, and her son is a physician. The other three children are engineers. Her daughter who is a dentist was with her on the day of the interview, and according to Salwa, her children who are medically trained often attended her medical appointments with her. Her daughter was not present at the time of the interview and chose to stay in the waiting area.

Salwa's journey with uterine prolapse started a year ago, she was experiencing a "bothering" sensation in her vaginal area while doing her household duties as a housewife as well as a "bit of heaviness". She did not seek medical support immediately but did after her symptoms got worse and she started experiencing recurrent urinary infections. She sought medical support about 6 months later at a private hospital that she often visits and was advised to manage her urinary symptoms initially because it was causing her a burning sensation and pain on urination; hence, the doctor prescribed her antibiotics, which she has completed the course before attending the clinic. In terms of her prolapsed uterus, Salwa was given two diagnoses: she was told first that she has prolapse then was told that she has vaginal wall thickening and was advised to undergo hysteroscopy for further examination. Salwa refused and requested a second opinion; thus, she attended the clinic for a second opinion on the day of the interview.

The interview lasted for twenty-five minutes. Salwa was happy to take part in my research, but she talked very little during the interview; especially when asked

probing questions. Moreover, during the interview she paused about 35 times and at times she appeared hesitant to speak about her feelings.

## 7.2.4. Dina

Dina is a 54 years old woman. She is married and has six children. Dina's eldest daughter is 28 years old, and her youngest daughter was born with a disability. Dina lives in her house with her husband and all six children, she looks after them, cooks for them, and does housework. Dina's wider family and her husband's family also visit them quite often, so she had been surrounded by her family, holding receptions, and fulfilling their needs broadly most of the time.

Dina said she has no help or support at home, which resulted in her being involved in housework, she has maintained her responsibilities towards her family even after she developed prolapse. Dina's experience with prolapse started four years ago but she has not sought professional support until recently when she stepped back from her responsibilities and decided it was time to take rest and seek healthcare support.

She was happy and welcoming to take part in my research and spoke a lot about her responsibility within her close and wide family and how it impacted her experience and vice versa.

## 7.2.5. Aziza

Aziza is in her early sixties. She is married and lives with her husband and a fulltime housemaid, who undertakes all housekeeping tasks. She has two married sons living in separate houses. She was a history teacher but has been retired for few years. She did not discuss her reasons for retiring but talked about how she spent her time after retirement.

Aziza had been experiencing symptoms of uterine prolapse for six months. Her symptoms started off as mild vaginal bulging that progressed over time. She also experienced a loss of bladder control that significantly affected her lifestyle. Aziza was waiting to have corrective surgery, although her operation had been cancelled twice because of hospital related constraints. Aziza refused to discuss how prolapse affected her marital relationship, but she spoke about her experience within healthcare and what it meant to her to live with prolapse and seek support as a religious woman holding strong beliefs.

## 7.2.6. Mai

Mai is in her early fifties and she has eight children. Her eldest daughter was 27 years old, and the youngest child was three. Mai has a bachelor's degree in education, but she has chosen not to work following graduation as she was occupied caring for her children.

Mai's husband is employed, and she was financially dependent on him and has been so since they got married. Their socioeconomic status was good, and historically, Mai has sought healthcare from private providers but, due to a recent reduction in her available budget caused by a house purchase, she has started to seek support at government hospitals.

When asked to take part in the research, she was welcoming and happy to participate. She was talkative during the interview. Mai's journey with prolapse started five years ago, she complains of three issues that she thought are distinct, namely: prolapse, urinary symptoms, and sexual dysfunction in form of being "wide". However, she did not take advice to have surgery but instead became pregnant again afterwards.

Mai came across as kind and friendly. She spoke openly about her experience and how she has been coping for five years. At times during the interview, it was challenging to follow and probe further but it was evident how disturbed and annoyed she is by the symptoms she has.

## 7.2.7. Zainab

Zainab is a 62 year old lady. She is married and has three sons and a daughter. One of her sons is a healthcare professional at the university hospital and he often accompanies her to her appointments, when Zainab had attended for treatment and was accompanied by her son.

Zainab's experience with uterine prolapse started six years ago, it mainly bothered her when she walked, and her marital relationship was also impacted by the condition. She sought medical care three years after experiencing the symptoms whilst in the UK, visiting her daughter who was studying there, and was offered a pessary. But after their return to Saudi, Zainab struggled to find a specialist urogynaecologist and experienced an unpleasant appointment at a private polyclinic, subsequently her son found her current doctor on social media. She attended the clinic to change her pessary and was happy to take part in my study.

Zainab talked about her experience with healthcare in the UK and in Saudi Arabia at both private and governmental sectors and highlighted the differences in care provision. She also shared her views on sex and spoke about the role of her family in her experience of healthcare.

## 7.2.8. Lujain

Lujain is in her early sixties. She is married and has five children. Lujain's children are all grown up and have left the house. She is unemployed and spends her time watching television or visiting her mother. Lujain has a housemaid who undertakes household work. She said that she is living a happy and comfortable life as there are not many expectations placed on her.

Lujain's experience with uterine prolapse started two years ago. She mainly complained of vaginal bulging during certain activities. Lujain has an active sex life, and the bulging was often noticeable during intercourse, this is not bothering her but bothers her husband, but they still maintain frequent intercourse.

Lujain's older sisters also have prolapse and Lujain at times appeared to view her own experience with the condition through the lenses of her sisters' experiences. Indeed, the symptoms she complained of were not much bothering to her, yet she was considering removing her uterus as she was aware it could get much worse in the future.

## **7.3.**The process of generating themes

During the analysis, as discussed in chapter (6), each interview was treated as a single case. The five generated themes were derived by first individually analysing each interview and identifying themes in the transcript (see appendix G). This step was repeated with all other interviews. At the final step of the analysis, the themes generated from all eight interviews were compared and contrasted to identify what was unique and what was shared between women in terms of their experience of prolapse. The identification of the shared themes through the unique bits of the women's experiences was only facilitated because I shared the cultural background with these eight women. The process of generating the themes is presented in appendix (I).

#### 7.4.Generated themes

## 7.4.1. Theme 1: Conceptualisation of prolapse

#### Introduction

This theme illustrates the participants' conceptualisation of prolapse. It involves three subthemes as outlined in table (5) that are: lack of knowledge, attributing causes to prolapse, and adapting to prolapse that also includes the self-managing techniques the women developed to manage the symptoms and live with prolapse. The idiographic thematic analysis process undertaken in this research (see outlined in appendix G) followed by cross-case analysis revealed that the understanding of prolapse was a shared theme that all eight women in this study spoke about. The women responded to the symptoms they were experiencing based on how they initially made sense of it. Therefore, it was decided to name this theme conceptualisation of prolapse as it provides an overview of how women understood prolapse and their choice of coping with the condition. The following section presents each supporting subtheme

#### 7.4.1.1. Lack of knowledge about prolapse

The length of the womens' experiences of prolapse ranged from six months to six years. Except for two women: Nabeela and Lilly, there was a consensus that women had no knowledge about prolapse prior to their experience of prolapse related symptoms. For example, Dina and Lujain said that they had no knowledge about prolapse; and therefore, they experienced fear and anxiety once they started experiencing the symptoms:

## "I was scared! I mean at first when I saw it" Dina

"I was worried I didn't know what it might be" Lujain

Zainab also indicated that she felt scared, but she was concerned that it might be cancer.

"I mean at first when it started about 6 years ago I was so scared, I didn't know where to go! I said maybe I have cancer, it descends more and more, more and more every time, I don't know why" Zainab

Relating her condition directly to cancer without considering any other possible health issues and wondering why it grew bigger in size reflects that Zainab had no previous knowledge about prolapse. Her discourse implies that noticing a lump or protrusion in the vaginal area might be an indication of cancer which is indeed a fearful diagnosis. In addition, it appears that Zainab felt lost particularly when she said, "I did not know where to go". It also demonstrated that she did not know whether this problem required healthcare support or maybe she did not know whom she could speak to for reassurance. Similar emotions were also reported by Aziza who said that she was fearful when she first experienced the symptoms, but she linked this to another traumatising experience in the past: childbirth, which was terrifying to her because her last labour was difficult.

# "I got panicked! When I first saw it I did not know what it was! I am telling you like a baby head, I was terrified!" Aziza

Zainab, Aziza, Dina, and Lujain provided these narratives when I individually asked them during the interviews about what their first response was when they first started experiencing the symptoms. It can be seen from the extracts here that these four women experienced fear and concerns about prolapse and they have attributed these emotions to their lack of knowledge about the condition or fears of what the condition might be. Lack of knowledge was also reported by Mai and Salwa. Mai's lack of knowledge was apparent when she reported the three symptoms of prolapse she was experiencing as three separate problems that were distinct from each other. While for Salwa, the lack of knowledge was evident as she personally indicated so. Lack of knowledge was further apparent as Salwa said she was advised to have hysteroscopy, yet she refused as she was anxious about the results that it might be a form of cancer.

Six of the eight women interviewed attempted to make sense of their condition and think why they developed a prolapse, this is presented under the next subtheme.

## 7.4.1.2. Attributing causes to prolapse

This subtheme demonstrates women's sense making process and the way they conceptualised prolapse highlighting the reasons for which they decided to cope with it. A wide range of causes have been linked by the women to their understanding of why they developed a prolapse. The first attributed cause was ageing that was reported by three women: Aziza, Lujain and Salwa. Aziza said that she assumed that prolapse could be because she thought she might have pelvic muscle weakness due to the ageing process. Linking prolapse to ageing was a result of Aziza's sense making and interpretation of the world she lives in, yet the way Aziza said this, and the use of words might reflect some deeper issues that resonate with her lifeworld:

## "Maybe I have weakness in my pelvis from inside, that is son of Adam this is his age" Aziza

By saying "son of Adam", Aziza meant "mankind". It felt, in Aziza's perception, that ageing was a form of deterioration of body functions that all mankind would eventually experience, and for Aziza, this was her time of declining in her health status. To point out, Aziza is 62 years old yet perceived she was experiencing signs of ageing. A further discussion of this is provided under theme (5). Lujain also considered ageing as a potential factor that caused her to have prolapse, she said:

"I also feel that it could be because of ageing, you see an individual develops sagging and loose skin with ageing, the tummy sags, the arms sags, so it is obvious that the uterus also loosens up and sags." Lujain

She provided a personal explanation of how advancing in age could affect the body including the uterus causing it to be loose and saggy, and by using the word "obviously" it felt that Lujain was certain that ageing is a potential risk factor for prolapse. Her rationalisation of the condition suggests that she perceived that having prolapse at her age was inevitable which implied her resignation to the condition. She was 61 years old, and she might have thought that she was old enough to start having her perceived signs of ageing. However, Lujain chose to discuss ageing as a factor in relation to women in general instead of reflecting on herself or indicating that she was growing old. It is possible that it was hard for Lujain to refer to herself and say that she was growing older, indeed, she has started

introducing herself by saying that she looked younger than her actual age. Nevertheless, despite her perception of herself to appear younger than her age, it was embedded in Lujain's understanding that experiencing prolapse was indeed a sign of ageing process.

Salwa also sounded certain when she said that ageing directly causes prolapse although she has indicated first that she had no knowledge about prolapse.

## "but it is the advancing in age what brings it, increased pregnancies and labours" Salwa

To point out, Salwa has sought healthcare support few months before being invited to take part in this study but did not receive any treatment for prolapse. This contradiction in her discourse might be explained by the possibility that when saying that she knew nothing about it, Salwa might meant to say she personally had no previous knowledge, yet it was maybe acquired or developed as she sought healthcare support or maybe from her son who is a physician.

Multiple pregnancies and childbirth have also been described by women in this study as another potential cause of prolapse. Four women, Dina, Lilly, Salwa and Lujain clearly considered childbirth and spacing between childbirth to be a causative factor:

"Pregnancy and labour have an effect, I got tired with every with every labour, each pregnancy and labour is different, they say the uterus sags, at the time of labour at the time of pushing, of course, the uterus drops" Lilly

Lilly asserted the impact of pregnancy and childbirth on developing prolapse while indicating that she felt tired after each delivery. She was certain that childbirth and frequent pregnancies were a causing factor for her to have prolapse, she has been pregnant eleven times, including three miscarriages. Lilly explained she had a baby every two years:

"not like every two years I had a newborn" Lilly

While this could be her personal choice, but how Lilly has expressed it and her tone of voice when she said this could suggest some deeper issues. I did not probe further on this issue with Lilly because of the shared cultural understanding between me and her that it might be too insensitive or judgemental to further discuss it. I understood that it could be that she had no control over choices in terms of pregnancy as it was a part of her expectations as a woman. This is further discussed under theme (5).

Similar to Lilly, Dina also said that spacing between childbirth was an issue for her:

"I mean I have 6 children and they were all close, I mean there were only two years between each delivery and another, it might be because of pushing during delivery maybe, maybe from housework, I was really exhausting myself" Dina

Dina thought frequent childbirth has negatively affected her uterus and she perhaps was regretting the frequent pregnancies at this stage which was elucidated by her facial expressions. It appears Dina was providing her perceived causes whilst indicating that she was uncertain by saying "maybe" and "might". She has also linked housework to developing prolapse but also was uncertain. Despite her uncertainty of the causes, the risk factors she mentioned seem to be significant to her, she spoke about these two reasons a lot during the interview and gave her explanation of how she perceived they might affect her. Her discourse suggests that she has been very involved in housework and now started to feel that it has adversely affected her health.

"I mean at first at first (Pause), I used to exhaust myself, I didn't have mercy on myself, I used to do this and do that and do so many things, and then I started to have some bleeding with it, very small amount when I am standing" **Dina** 

Dina's interview suggests that there were certain gender role norms and different expectations of men and women. Housework and hosting receptions were parts of expectations from her as a woman. Women are expected to be involved in housework, Dina thought that women often subconsciously do too much housework, and she had no control over it. This is further addressed in theme (5).

By looking at Dina's discourse, and that of other participants, it can be seen that being involved in housework was also assigned as a potential cause for prolapse. The amount and extent of housework reported varied across the women, some perceived lifting a water gallon as a heavy object, while for others lifting heavy objects meant lifting a gas cylinder or a fridge. Many women reported their lack of rest and being consumed with housework until they developed prolapse. Lilly said that she also has been involved in lifting heavy objects around the house intensively.

## "I suppose it because of lifting, (Pause) we don't have mercy on ourselves, we would carry anything, a fridge, a gas cylinder" Lilly

Lilly here was speaking about lifting heavy things in the context of herself and her sisters, and the effect it had on them by causing them all to have prolapse. When Lilly said that they did not have 'mercy on themselves', she was aligning her experience with that of others. It could also imply that lifting heavy objects around the house was expected from her as a housewife and part of her responsibilities. Indeed, when Lilly first started talking about her experience with prolapse, she immediately stated that it was because she was a woman and was often involved in lifting heavy objects around the house, it felt that she was normalising this as part of her roles as a woman. Her discourse suggests that she perceived this to be common among women because she and her sisters were doing so.

Lujain also indicated that she occasionally lifts objects she perceived to be heavy around the house which might have caused her to have prolapse:

# "I said maybe it is from lifting, sometimes I lift like a water gallon or push something heavy, maybe." Lujain

Generally, it was noted that the societal expectations from Lilly and Dina were similar, and their perceptions were also alike, but Lujain's experience was different from theirs. Lujain said she was living a comfortable life but thought that lifting heavy objects occasionally or pushing furniture might have caused her to have prolapse. But she was not certain if it was relevant to cause her to have prolapse as she began the sentence and ended it by saying "maybe".

Nabeela was another of the participants who thought that housework might have caused her to have prolapse:

"I had about two years ago, and before that I swear there was nothing wrong with me. It was Eid holiday and maybe I carried a lot of stuffs and put them in a bag and I got tired from carrying and putting, glory to God, maybe this is why I had it. That day I remember I made an effort and then I went to the washroom and I was bleeding. Praise God, maybe it was written for me in my destiny to have this that I got tired and tired, and when I collected all the stuffs at home and put them all together in bags and carried them, there were a lot of bags may 5 or 6 bags." Nabeela

Nabeela said she noticed that she was bleeding after lifting heavy bags around the house during the holidays and that it might be the reason why she developed a prolapse because she felt she made quite a physical effort that day. Nabeela also said that she might be destined to have prolapse. Her discourse suggests that she felt that she had no control over developing prolapse, and there seemed to be some level of acceptance as this was her destiny It is possible that Nabeela thought that having prolapse was inevitable given her reasoning for her faith in God which reflected the position of religion in her life. Nabeela also perceived prolapse to be a hereditary condition, and her understanding was based on seeing close family members experiencing prolapse.

"this is a hereditary condition, my grandmother, my mother's mother had a descending uterus, and my mother's uterus also descended" Nabeela

Her grandmother had it, and her mother also had it; respectively, Nabeela made sense of it as a hereditary condition that possibly all women in her family had it or eventually would have it. Dina also thought family history to be a potential reason why she had prolapse, but she did not involve it much in her discussions similar to childbirth and housework. She talked more about the link between her prolapse and housework and childbirth than the shared family experience.

"I don't know, maybe it is hereditary? My aunt was like this, and they just removed her uterus, but I don't know if its hereditary" **Dina** 

She begun by acknowledging first that she did not know why it happened to her and then she identified prolapse as a hereditary condition whilst indicating that she was uncertain by saying "maybe" and "I don't know". Regardless of the way Nabeela and Dina linked prolapse to family history, this suggested that they made sense of it as something that they had no control over or perhaps expected.

Early marriage was also considered a potential reason for prolapse but only by one participant: Lilly, who married at a young age and indicated that her sisters also married at an early age, and all ended up having prolapse.

"my older sister got married at 8 can you imagine !! a child !! if you get married and haven't had your first period yet it is so hard, deadly hard !! not like when you are an adult, it definitely affects the drop." Lilly

Lilly said that early marriage has a damaging effect, she was not precise about what the effect was or what was being affected but considering the context of her narrative, it appears that she was referring to her uterus. Lilly then rationalises early marriage as a potential cause for prolapse, it seemed that sex may have been what Lilly was referring to. It suggests that she's talking about sexual intercourse prior to menstruation and lack of body readiness for it to happen She might be talking about it this way as she perhaps was not comfortable mentioning sex in relation to early age marriage. Lilly said she and her sister got married and perhaps had sex at a very early age which Lilly felt it had also caused them to develop the condition.

This theme presented the participants' conceptualisation of prolapse. It first demonstrated that women had no knowledge about prolapse prior to their experience which was evident from the anxiety in their narratives. This theme also reported the causes women attributed to prolapse that mainly were advancing in age, childbirth, housework, family history, and early marriage. The reported risk factors suggested that women's perception of prolapse as an expected condition following these risk factors but did not view it as an illness or a health condition requiring intervention.

The next subtheme demonstrates the approaches women used to help them adapt to their condition in order to carry on with their everyday lives and maintain fulfilling their roles and expectations.

#### 7.4.1.3. Adapting to prolapse

Adapting to the condition was the first response of women to prolapse. Nearly half of the participants attempted to self-manage their symptoms or developed personal coping strategies. These strategies were divided into those linked to traditional medicine, those discussed by family members or ones they tried themselves. Resting and lifting the uterus through upward massaging of the abdominal area either personally or with the help of a traditional medicine practitioner has been reported as one of the coping mechanisms.

Mai, Nabeela, and Salwa indicated they sought the support of traditional medicine to lift the uterus up through massage and learn the technique so they would continue doing it at home when they felt tired or when it was needed for comfort. The potential triggers for seeking the help of traditional medicine practitioner from a shared cultural perspective is presented under theme (5).

"I don't feel comfortable unless I am lying on bed and lift it up with my hand, or I let a masseuse lift it." Mai

She continued:

"I have been there once, not now but a while ago, but now I do it to myself, I rest for 2 to 3 hours and don't move and don't make any effort and rub some olive oil and keep lifting my tummy up, this way I feel I am lifting the uterus up with my hand you get me? But this is just temporary" Mai

Mai said the results of this technique were not long lasting in terms of relieving symptoms, but she would often do it for temporary relief. The pain Mai described

she experienced as a result of prolapse was not problematic to her and she did not consider it to be a healthcare issue despite suffering for four years. For her, the sexual implication of prolapse was more disturbing, she coped with it as she was immersed in her responsibilities and had to get on with her busy life, this is further discussed under theme (4).

Seeking support from a traditional medicine practitioner was also reported by Nabeela as a first step after experiencing prolapse symptoms:

# "when she came to see me, and she confirmed that my uterus is descending extremely descending." Nabeela

The experience of Nabeela's mother with prolapse has greatly informed her own experience. She said her mother was advised by a traditional medicine practitioner to rest but she never listened. Traditional medicine seemed to be the only way of managing healthcare problems in the old days according to Nabeela's narrative. There seemed to be a strong belief that traditional medicine broadly was the cure for all healthcare issues, and she perhaps thought that it might have worked with her mother if she agreed to rest for a while because rest is a way of managing prolapse and helps improving after traditional medicine treatment.

Nabeela felt that the traditional medicine practitioner was the first one to confirm with her the diagnosis of prolapse. She then spoke about the management that was given to her and its effect, she said:

"when the traditional medicine doctor rubbed my tummy the uterus was elevated, it was helpful for the 1st day then it started descending again lower and lower" Nabeela

Nabeela said that she noticed that traditional medicine massages provided her with short acting relief, but she also noticed that her condition got worse afterwards. Nabeela did not mention whether or not she sought the support of a traditional medicine practitioner again rather she said that she sought healthcare support afterwards. Her response suggests that traditional medicine is not a suitable management approach for prolapse which oppose Nabeela's beliefs of traditional medicine being the ultimate cure for all health problems.

Salwa also said that she has tried seeking the support of traditional medicine but was reluctant to do so:

"they told me there is one Asian masseuse, but I swear I don't like these things, I brought the Indonesian and she did a massage for me as you would say, lifting and massaging, I don't remember doing anything else." Salwa

But she was unhappy with the experience neither she was convinced with the approach itself or its usefulness. It appeared that it could have been peer pressure that made her try it as she was advised by her sisters and friends to do so. Salwa stated she essentially tried other ways to manage her symptoms by simply stepping back from the activities that aggravated her symptoms of prolapse such as walking, going to the gym, and intercourse:

"I used to go to the walking path, I also was registered to a gym, and then I stopped because I heard that it affects the prolapse, and it's also affected by walking, so I stopped going to the walking path and the gym after the problem started." Salwa

She added:

# "Yes it bothers me, but I have stopped intercourse since the problem started" Salwa

Salwa's decision to stop intercourse soon as her condition started could imply that she thought it was a personal decision that involves her only, this is further explored under the theme prolapse and marital relationship (see later).

Dina said she would rest and lie down when she was in pain as an attempt to selfmanage the symptoms:

# "When I see myself feeling sick go and lie down until I feel relieved and then get up and do the things that I want." **Dina**

It is understood from her narratives that resting and laying in bed helped in easing the symptoms, however, doing so would require her to step back from her responsibilities as a full-time housewife. Thus, she decided that she would not do any housework in order to manage her condition

"But when I am resting and lying down there is nothing, that's why I said when I am lying down and resting I feel fine so I am not doing anything from now on" **Dina** 

What is further understood from Dina's narrative is that her experience of prolapse and her adaptation techniques have impacted her active roles within her family, and this might have an implication on her husband's response towards her condition, this is explored later on.

#### Summary

This theme demonstrated womens' conceptualisation of prolapse. Lack of knowledge was apparent across the majority of women; two women only knew prolapse prior to their experiences. Women attempted to make sense of prolapse through attributing five causes to developing the condition: ageing, childbirth, housework, early marriage, and family history. These causes suggested that women felt experiencing prolapse at this point given these factors were inevitable. Four women developed coping strategies to live with the condition. The methods these four women described they used to self-manage their symptoms may not be sufficient to reverse the prolapse or control the progression of the condition. The women chose to adapt to the condition and developed certain self-management strategies in order to cope with the symptoms of prolapse such as traditional medicine massage and stopping activities that trigger pain. These approaches appear to have helped them to adapt to the condition and live with it in accordance with the available resources for them in addition to their understanding of it. They have coped with their prolapse for between few months up to few years without seeking professional support.

## 7.4.2. Theme 2: Social support provided by family

#### Introduction

Family was one of the broad themes identified during the analysis and was common across all study participants. Family was reported to be involved in the lives of women in multiple ways. It included their close family such as husband, children, mothers, and sisters, and it also included the wider family such as their aunties and husband's family. Women had responsibilities towards their families and apparently, they had expectations from their families as well. Essentially, family was important to the study participants, some indeed identified family as part of their identity and indicated that there were certain roles and obligations expected from them and these roles were disturbed because of prolapse symptoms. Seven of the eight women were housewives, and one was a history teacher but retired before experiencing prolapse.

This theme presents the role of family in the experience of women with prolapse. It includes two subthemes: disclosing illness and receiving support. This theme was named social support provided by family because for women in this study, family formed a social circle where women could share their intimate concerns, be listened to, and receive various forms of support.

## 7.4.2.1. Disclosing the experience of prolapse

It has been addressed in the previous theme that women had an apparent lack of knowledge about prolapse and perhaps understood it as something expected to happen to women. It felt that women needed confirmation from other women in their social context that they all have been or are going through the same changes. Prolapse was also disclosed to husbands possibly because it cannot be kept hidden from them, but this will be addressed separately in theme (3).

All of the women interviewed have broadly indicated that they disclosed their experience of prolapse only to women in their families specifically their daughters, mothers, and sisters, some also spoke to women in their wider family. Speaking to other women in the family was women's first attempt of disclosing and sharing their experiences within their social context although prolapse can be perceived as a sensitive condition in Saudi Arabia due to its relevance to sexual related health. The decision of whom to disclose the experience to was relevant to the strength of the familial bond that ties these women to their families. Further exploration of this is presented under theme (5).

Aziza said she spoke to one of her sisters and indicated that her sister had prolapse that has been surgically managed:

"I spoke to one of my sisters she has an operation done for it, she has done two operations, my two sisters have done it! My sister (A) in Riyadh has done it twice and now they have put supporters in her she does not want to do the operation again, now every two months she puts the supporter, and (B) no she has done it once and she is doing fine". Aziza

Aziza did not speak about her other family members in respect of her prolapse, but she refused to speak about the implication of prolapse on her sex life. Nevertheless, talking to her sister demonstrates Aziza's willingness to share her experience of prolapse with at least one of her female family members. Aziza said that both of her sisters had prolapse and had sought healthcare support for managing it. It was unclear at first whether she knew about her sisters' experiences before developing the condition herself. Given her reported lack of knowledge which has been discussed earlier under theme (1), it can be argued that she did not know about their experiences before deciding to speak to her sister.

Lilly, Lujain, and Mai also have shared their experience of prolapse with close family members. Lujain said she spoke to her mother as soon as her symptoms started due to the feelings of anxiety she had because of the symptoms she was experiencing.

"I was worried I didn't know what it might be. Then I called my mother and told her about it and she said that even my sisters have the same problem. (Pause). But mine is not as serious as theirs." Lujain

She had the willingness to share the burden of the experience with those closest to her. Indeed, Lujain's mother seemed very close to her as she has indicated that she often visited her during her free time. Lujain's mother shared the similar prolapse experiences of her sisters with her in some great detail. As presented in the theme above, Lujain had no previous knowledge about prolapse, and after speaking to her mother and the details she has shared with her, this has become a source of information for Lujain about prolapse in general. It appeared that Lujain's knowledge about prolapse was built through comparing her condition to her sisters. Respectively, Lujain felt that she was not experiencing a serious health condition at this stage

Mai said that she occasionally asked her sisters for advice and discussed the potential solutions with them but indicated she would not share detailed information with them because she thought that it was a private matter.

"I often talk to my sisters about what should I do and so, but even my sisters I don't tell them all, maybe there is only one sister who I tell her everything otherwise no I am really embarrassed to say these things to anybody its private." Mai

The experience of prolapse appeared to be different for Mai than the other participants. Indeed, prolapse was not as problematic to her as the sexual implications of prolapse (see section in theme 3). She described that she has spoken to her sister about her problems but would not share information relevant to her intimate life. It might have seemed difficult for Mai to share her personal experiential concerns with her sister possibly because of the age difference as Mai indicated that her sister was ten years older than her. Nevertheless, Mai in her narrative broadly said that she finds difficulty sharing such information not only with her sister but with anybody around her, which might suggest that this is indeed a personal issue to Mai and it could be relevant to her cultural and religious beliefs (see theme 5).

Dina on the other hand said she has shared her problem with her wider family but they exclusively to women when she was visiting them:

"See when my family saw me sick, they were asking me what's wrong with you? what's wrong with you? I used to tell them that there is something like a ball coming out, I didn't know it's my uterus that is coming out" **Dina**  Dina perceived her commitment to her family as a part of her identity, she began the interview by introducing herself as a *"housewife"*. Dina seemed to be surrounded by her family for so long, her children were at home even though they were in their twenties, and she was still looking after them. Moreover, her family and husband's family visited Dina quite often. The effects of living with prolapse in terms of pain and discomfort were broadly overlapping with Dina's roles and commitments to her family. Family, indeed, was central to Dina, and her experience with prolapse somehow revolved around her commitment to her close family: her husband and children, her wider family or relatives. Hence, sharing her experience with her family: close or wide reflects the commitment she had towards them. She might have felt comfortable discussing prolapse with them, or maybe, she had to tell them about her experience of prolapse due to the evident change in her roles as a consequence of prolapse. This is further explored under theme (5).

#### 7.4.2.2. Receiving support

This subtheme describes the responses of the womens' families when they disclosed their prolapse and its impact on them. Following disclosure, all women described the various forms of support provided by their families. This included informational, emotional and practical support.

In terms of informational support, Dina, Aziza, and Lilly were given information about prolapse by the women in their families whom they disclosed their illness to and all three were advised to seek professional support. This information was provided by the women in their families who had experienced prolapse in the past and received healthcare treatment for it.

# "my sister shouted at me, she is older than me, that this is your uterus go to the hospital!". **Dina**

Dina said that her sister had responded by advising her to seek healthcare support. She also, later on, indicated that she was informed about the experiences of one of her relatives with prolapse and was provided with information about the available healthcare approaches based on her relative's experience and Dina then suggested what would be the best option for her:

# "One of my relatives had it before and then she did an operation to remove the uterus." Dina

Dina indicated that she first did not know what was happening to her, it might have not occurred to her that her problem required healthcare support until her family advised her to do so. She was informed by them that there are two methods for the management of prolapse: surgical lift and hysterectomy, she described she was more inclined towards hysterectomy.

"Because there are lots of people, they say they have done an operation but did not remove the uterus, but it hangs just for 5 years, 5 years and it comes out again. I don't want it like this, I mean now I do the operation and then wait to do it again? I really don't want this, because I know someone who has done the operation without removing the uterus and it came out again." **Dina** 

This narrative indicates that the information Dina received from her family has shaped her expectations and demand from healthcare.

Aziza also said that she was advised to seek professional support when she disclosed her illness to her sisters and that what she was experiencing was a health condition that required medical intervention.

"They told me to go to the doctor, I told them when this ball came down of me at first before I go to the doctor". Aziza

Aziza was also told about the management approaches for prolapse, but this did not appear to impact her choice of desired treatment.

Lilly described that all her sisters had prolapse and spoke about why they all ended up having this issue and this has been discussed in the theme above.

# "I told her what I have and she has been telling me that it's a drop drop drop " Lilly

As prolapse was a common problem in Lilly's family; she and her sisters had given it a specific name. Instead of saying prolapse, Lilly has used the word "drop" frequently and it felt like a diagnostic term that she and her sisters used when they identify any potential prolapse symptoms. Lilly's sisters shared their problem with prolapse with her, and Lilly shared her experience with her sisters as soon as she started to have the symptoms and her sister asserted that it was the "drop".

Lujain felt that disclosing her illness to her mother has provided her with emotional support or reassurance given that she was concerned about prolapse due to her described lack of understanding about the condition.

# "she said that even my sisters have the same problem. (Pause). But mine is not as serious as theirs." Lujain

The information about her sisters was given to Lujain by her mother. She did not mention if she shared her experience of prolapse with her sisters even after knowing that they had similar problems. Nevertheless, it was understood that she did not, and Lujain further did not provide reasons for why she had not spoken to her sisters about her experience. It is possible that this was because they did not share their experience with her directly either.

"I don't feel anything else unlike my sisters. They haven't done any operations or anything. (Pause) I mean my older sisters, the eldest has her uterus really descending, the other one I mean is less than the 1st one but more than mine" Lujain

Through constantly comparing her condition to her sisters, Lujain might have understood that it is possible for her condition to get worse over a period of time. It appeared as if she started to have future related concerns about how prolapse would progress over time affecting her ability to control urine.

"But they say if I leave it as it is for a while (Pause) for 5 years 10 years, it goes down more, but I don't know. (Pause), so then it goes down even you cannot control your urine, that's why I got scared"

## Lujain

As her knowledge was developed through reflecting on her sisters' experiences, it felt that Lujain was viewing her own experience through the lens of her sisters' experiences. She seemed immersed in what would happen to her in the future and controlling the progression of prolapse symptoms, while paying little attention to the symptoms she actually had. This extract also suggests that not prolapse but the possibility of developing urinary symptoms was concerning to Lujain. In fact, during the interview she mentioned that she was willing to live with prolapse without any management but decided to seek support for reasons explored under the next theme.

Nabeela, Zainab, and Salwa reported receiving practical support specifically managing access to treatment rather than the prolapse itself. These three women indicated that their children, both males and females were involved in their experiences. Their children would make their appointments and take them to hospital. Nabeela did not directly say that she spoke to her children about the prolapse but their involvement in her hospital visits and appointments suggest that she did speak to them. This is further elaborated under theme (4).

Zainab also spoke about her children's involvement in her healthcare experience. To begin with, she sought support in the UK because her daughter was there, and that she and her daughter went to the hospital together.

# "I travelled to the UK my daughter used to study there, we went to see a British doctor" Zainab

When Zainab was back in Saudi Arabia, her son was the one who found the doctor for her.

# "then my son saw Dr, (I) on phone, he said they say she is good, my son is a doctor here" Zainab

It appeared that her children took responsibility for finding a suitable doctor for her and taking her to her appointments. When Zainab first had her prolapse, she waited until she was in the UK to seek healthcare support with her daughter despite her son was a healthcare professional working at the university hospital. This is further discussed under themes (4) and (5). Similar to Zainab and Nabeela, Salwa's children were also involved in her experience which suggest she had spoken to them about her condition. Hence, her children would attend her appointments with her:

"my son was with me that day, he sat and obviously he is a doctor and was discussing with her" Salwa

#### Summary

This theme demonstrated the social support provided to women by their families. All the study participants disclosed their illness to at least one woman in either their close or wider families. The trigger to share experiences with female family members was unclear and not fully explored in the interviews but it could have been driven by their lack of knowledge and need to rationalise their prolapse as an expected condition following identifying certain risk factors. It felt that the women wanted reassurance that other women were going through the same things. Women received different types of support by women in their family: informational, emotional, and practical support. A few of the women's children were also involved in their experience providing them with practical support in terms of assisting them with approaching and accessing healthcare support. It appeared that the women in this study have also shared their experience with their husbands possibly because it cannot be kept hidden from them. The following theme presents the implication of prolapse on women's marital relationship and it also covers the response of their husbands.

## 7.4.3. Theme 3: Prolapse and Marital relationship

#### Introduction

This theme seeks to explore the implication of prolapse on women's marital relationships. It includes four subthemes: physical impact and altered body image perceptions, the implications on intimate life, the meaning of sex, and the response of husband. Being married was one of the inclusion criteria for the women in this study in order to respect the cultural sensitivity when discussing such intimate issues in Saudi Arabia. All the women in this study were married but only five of them described having an active sex life, two did not, and one refused to speak

about this aspect of her life. Naming this theme prolapse and marital relationship seemed appropriate as it provides a possible view about women's sex lives, their perception of body image after prolapse and how they thought their husbands responded to it.

### 7.4.3.1. Physical impact of prolapse and altered body image perceptions

The analysis of data revealed that many women with prolapse had altered body image perceptions that were a result of the physical impact of prolapse. Aziza, Nabeela, Lujain, Dina, Lilly, and Mai have specifically indicated that prolapse has described how prolapse looked like to them and that it disturbed their body image, but they all have stated it differently. Aziza has described it (the prolapse) as a baby's head at the time of labour and it has been presented under theme (1) that she has linked it to a traumatising experience in the past which explains her description of it.

It was presented earlier that Lilly and Aziza said that their prolapse looked like a ball descending from the uterus. Lilly further resembled her prolapse to a ball that traps her urine in, and she has linked feelings of being tortured to it:

## "the urine does not come out and this is torturing me" Lilly

Lilly used the word "torture" to describe the severity of pain. The effects of the regression were not only physical but there was also some level of psychological implication as Lilly said:

"I started to neglect myself, you start to have a mental state, you don't want to go out, you just neglect yourself and that's it, I don't know whether it's with everybody or just me." Lilly

Lilly said she eventually ended up neglecting herself because of what she has been feeling. The word torture suggests that this issue has significantly affected her mental wellbeing. She was uncertain if self-neglect was common after prolapse or whether she was the only one feeling it. Lilly described what she was going through as a 'mental state', this seemed that it was something internal and personal that she perhaps wanted to deal with alone. Perhaps she did not want to discuss it with

anyone, even with her sisters who have been through the same experience which could explain her uncertainty about this mental state. Her discourse suggests that she was feeling isolated despite having women surrounding her sharing similar experiences with her, this is further discussed under theme (5).

The self-neglect Lilly was referring to could be due to the pain she was experiencing but it also could reflect the way she felt about herself and her body after prolapse. Moreover, as prolapse was blocking the urine in, Lilly might be inclining her self-neglect to the feeling of being unclean.

Aziza also described her prolapse as a ball. To point out, Aziza was also experiencing issues similar to the ones Lilly was experiencing, particularly, the urine being trapped in as a result of the uterus being out. Their choice of words suggests that UI in the presence of prolapse resulted in urine being trapped affecting the way the bulge feels. Nevertheless, Aziza and Lilly were not the only women who had UI and prolapse together, Mai also experienced these two issues together, but she did not use such words to describe it, nor did she indicate feeling that the urine being trapped in. This potentially could be a result of the type of prolapse they were experiencing that resulted in the difference in the experienced symptoms.

Nabeela's discourse also suggested that might have had altered body image perceptions but also a major physical impact of prolapse, she said:

"I feel a descent in my uterus its descending, descending, imagine it even blocks the urine passage!! And now I even can't sit on the floor! It's very descending extremely descending! I can even hold it between my fingers, like if its hanged a bit and descending, and there also comes tummy ache and back pain and pain on my knees" Nabeela

She further added:

"even when I wipe with tissue I find blood sometimes. Blood because the meat is out, glory to God, like if it's going to inflame." Nabeela Nabeela said that she felt her uterus was almost out of her and was barely hanging in her pelvis, she also used a very powerful statement to describe it, she indeed described it as a piece of meat that caused her occasional bleeding. Her narrative reflects Nabeela's perception of herself to be sick following prolapse, she has repeatedly mentioned during the interview that she was extremely sick and wanted to receive urgent treatment for her prolapse. Nabeela's experience of prolapse appeared to be shaped by her mother's experience with the condition. She was with her mother when she had hysterectomy and indicated that she has seen her prolapsed uterus before the procedure. This may suggest that the disturbed body image she developed following prolapse was relevant to prolapse itself but also informed by what she has seen with her mother whom Nabeela thought had a more advanced stage of prolapse than her.

Dina's body image perception following prolapse was similar to Nabeela's, she also felt that her uterus was almost out:

"I am scared of it, I am really scared of it, when I see it coming out, I just don't want to do anything, I am afraid that it all might fall out of me!" Dina

It perhaps felt here that Dina has somehow lost her attachment to this part of her body, it seemed as if was no longer a part of her, she separated her prolapse from her body. She was not worried about herself rather she was scared of prolapse itself. It was presented under theme (1) that Dina would only rest to manage the condition when she felt her uterus was out, it was the reason for limiting her from fulfilling her roles as a housewife. She has linked feeling fear and anxiety to her prolapsed uterus and was concerned that one day it might fall out of her body, which may justify her desire for hysterectomy.

Mai indicated that she felt "wide" but discussed it as an issue separate from prolapse:

"In all my labours they cut me from down there, and this is why I feel wide" Mai By wide here Mai meant enlarged vaginal opening. During the interview Mai was referring to this issue by saying "I feel myself wide", it felt that, unlike Nabeela and Dina, this part of the body was intimate to Mai. To her, an enlarged vaginal opening meant that she personally was wide. It has been stated above that Mai felt that the sense of being wide was distinct from prolapse. She understood it as a separate problem that was caused by episiotomy, a procedure which she had eleven times. Thus, Mai felt that the change in her sex life was a result of her being wide not prolapse, this is further addressed next.

#### 7.4.3.2. Implications on intimate life

As it is understood from the given interview extracts above, prolapse has caused women to have physical changes and develop altered body image. The majority of sexually active women reported sexual dysfunction or difficulties following prolapse. This part of their experience would have been difficult to identify if nonmarried women were included in this study as Islamic rules mean that women are not allowed to engage in sexual activities unless they are married. Out of the eight women interviewed, six indicated that they had active sex lives before prolapse and that the effect of prolapse on their sex lives was detrimental.

After developing their prolapse symptoms, three women maintained active sex lives, and three decided to stop intercourse.

## "During intercourse, it gets more prominent, it comes out more like this and it is red in colour" Lujain

Lujain said that she only noticed her prolapsed uterus during intercourse. She did not mention if she was bothered by it, but her discourse indicates that she is more self-conscious during intercourse and therefore notices it. She might not have verbally indicated sexual dysfunction but what she said suggests that there was some degree of discomfort as it would come out more during intercourse.

Mai, as discussed earlier, indicated that she was experiencing sexual dysfunction as a result of being "wide":

"I feel myself really wide, uncomfortable and unhappy. I mean it is extremely wide!" Mai

She continued:

"you feel you are unhappy with this thing "intercourse"; I mean it is so regular, you understand, the world down there is really wide!" Mai

Mai was saying that being wide has caused her to have sexual dysfunction and the inability to feel anything during intercourse. It could be she meant that she has reduced sensation in the vaginal area due to enlarged vaginal opening or it could imply other sexual health related issues. Mai expressed her frustration with this issue and indicated that she was not happy.

Salwa, Dina, and Lilly all described having active sex lives before developing prolapse but decided to stop intercourse after experiencing the symptoms. Salwa said:

"It tires me during intercourse, with the intercourse and penetration it tires me" Salwa

She mentioned that prolapse has caused intercourse to be tiring. She later said that she stopped intercourse after she experienced the symptoms of prolapse specifically tiredness.

Dina also indicated that prolapse affected her intimate life, she makes excuses to avoid intercourse:

"It even affected the relation; I mean sometimes he approaches me, and I tell him I am sick" **Dina** 

She further said:

"I am sick, I feel nothing I don't have any desire, but I feel sorry for him, that's why I gave him my permission to get married if he wants."

Dina

Dina's discourse here suggests that the prolapse makes her feel unwell thus she decided to stop having intercourse and offered her husband an alternative to seek another wife. Despite what she was saying, the inability to have intercourse did not seem to be directly linked to physical symptoms of prolapse, as Dina has said that she had "no desire" for sex but it could be due to psychological consequences i.e., fear. Dina mentioned that she was injured in her prolapsed uterus once and managed it through the use of vaginal douche and medications. Dina later indicated that she felt afraid each time her husband wanted to have sex because she was concerned that she would end up injuring the uterus again, but Dina did not say if the previous injury resulted from sex or something else. She added:

"Every time I sleep with him, I get so worried yes that it might be raptured again, I don't feel comfortable when I do, I feel nervous."

## Dina

Dina's discourse suggests that it was not the prolapse itself that was bothering but it was the consequences of prolapse or the implications that were disturbing and made her feel sick and eventually she decided to stop having intercourse.

Lilly felt that prolapse had a direct implication on her marital relationship, particularly her sex life. Lilly said that her sex life was greatly disturbed since she had the symptoms.

"It became extremely bad. (Pause) It was so different before. Since I had the symptoms and I no longer accept this thing, I can't anymore. (Pause) It's too hard for me (penetration), you have a pain you can't, (Pause) I escape for 3 or 4 months" Lilly

By saying "it was different before" and comparing her sex life before and after having prolapse suggests that she was happy with sex before developing the prolapse. And after developing the condition, Lilly said that she would 'escape' for a couple of months, it seemed that she meant that she avoided sex at times to escape the pain. This might indicate that she had an active sex life but perhaps often refused to sleep with her husband in order to avoid the pain.

#### 7.4.3.3. Response of husband

It was indicated earlier that the women interviewed had to disclose their illness to their husbands possibly because it cannot be kept hidden from a husband, particularly for those who had an active sex life. The six women who had active sex lives before developing prolapse: Salwa, Mai, Zainab, Dina, Lilly, Mai, and Lujain shared the responses of their husbands to their prolapse. The responses of their husbands to the impact of prolapse were specifically related to their sex life and were varied. Their responses ranged from them being completely understanding of the condition and accepting its impact on sex (Dina's Husband) to forcing the wife to find a solution to her problem (Mai's Husband).

Two women, Mai and Zainab, reported that their husbands' responses to their condition were forceful, and these women have accepted it and attempted to maintain an active sex life despite being disturbed by the condition. Mai described her husband's response towards her condition, his response towards the symptoms she was having was accepting apart for the symptom of her being wide even though this may not have been linked to the prolapse (see earlier):

# "he told me you are really wide why don't you tighten yourself or do something about it?" Mai

Mai's narrative suggests that her husband was not understanding rather she was demanding her to tighten her vaginal area as if it was something she was able to personally do. Mai has personally tried many approaches to solve this issue and used different unauthorised substances in order to manage her problem. This response of Mai may reflect the superior position her husband obtained in the marital relationship as she perhaps felt obligated to fix this problem. Mai indicated that she felt that the issue of being wide affected her marital life, and this was evident indeed when she spoke about how her husband reacted to it. She said she was personally unhappy with her sex life and felt that her husband was also unhappy, which might have increased the burden on Mai.

"And even he is unhappy and feels it is too regular, to an extent that he would ask to do it from behind! Meaning you are really wide down there, and you have relief me by any other way." Mai Mai felt that as her husband was unsatisfied with vaginal sex, he would ask her to have anal sex and it seemed that she accepted that, which perhaps meant that sex was important to her as it was important to him or that it was the only way to keep him satisfied. The way Mai said this suggested her defeat and that she must do something about it particularly because anal sex is prohibited in Islam, this is further discussed under theme (5).

As she was unable to make him happy despite attempting to manage this issue and accepting to have anal sex, Mai ended up having concerns about her marriage:

# "I mean you bear in mind that he is unhappy! I was worried that he will go out or anything else" Mai

By saying "he will go out" Mai perhaps meant that she was worried that her husband would have extramarital relationships or seek another wife to fulfil his sexual needs as she felt that he was unhappy and dissatisfied with their sex life. Mai then spoke about what sex meant for her husband:

"He also had depression a while ago and I felt that the sex was extreme like crazy, and I hated it sometimes, do depressed men like sex? Have you heard about such a thing?" Mai

Mai thought that intercourse would be extreme at the times her husband was depressed. It was not clear what Mai meant by extreme, but it is possible that she thought that it was the only thing that took him out of depression. Hence, it was perhaps important for her to ensure that he would be at least sexually happy if he was ever depressed. Mai was very open in talking to me and sharing the impact of prolapse on her marital relationship in some great depth. She shared certain intimate information such as having occasional anal sex despite we both knew it is religiously prohibited in Islam. She might be desperate to talk about some of the issues and the confidentially I assured her during the consent process made her feel safe.

Zainab also indicated that she was forced to maintain an active sex life:

"May Allah guides him he still wants, what can I do? I be patient, sometimes blood comes out of me when he does it to me I bleed. But what shall I do? I tolerate because I want to make him happy, I don't want to upset him, I am afraid that he might get married and has kids and my kids suffer because of it" Zainab

The implications for her in refusing sex were far reaching, it could impact her children and therefore she could not refuse. It sounded as if Zainab was helpless, she has no choice but to sleep with her husband despite having bleeding as a side effect. When she said, "he does it to me", there was a sense of being passive and some level of compulsion. Zainab said she was obligated to make him happy as she was concerned that he might seek another wife because she felt it would have consequences that she thought would affect her children.

Zainab said that she has tried warning him that it was not good for him to have sex with her, neither it was good for her to have sex:

"He is fine with it, he does not mind, at first I used to cry when he says he wants me I cry. But I tolerate it what shall I do, I tell him it's not good for you either." Zainab

Despite her concerns sex was something she describes being pressured into continuing.

Lujain felt that the vaginal bulging resulting from her prolapse has been interfering with her intimate relationship with her husband. Her husband has told her that he was bothered by the prolapse during sex and has made some changes to adapt:

"I am telling you he lifts and penetrates from underneath, that's the only issue (Pause) that he is bothered (Pause) He told me that he is bothered a bit but he said he has no problem with it, otherwise there is frequent intercourse." Lujain

Lujain felt that her husband was bothered by the physical unease of intercourse that resulted from prolapse. He also told her that he had no problem with it and maintained active sex life by finding a way that Lujain felt that it has made it easier for himself. She felt that his response towards her condition was influenced by her response towards her own condition, she indicated that she was not bothered by her condition, and she felt her husband did not have any problem with it apart from being bothered by some difficulty during sex. Yet, despite his response and him comforting her and telling her it was not a big deal for him, Lujain still perceived this to be an "issue". She seemed to be very passive in her response to the prolapse and her acceptance of her husband's response

Dina said that her husband is very understanding of her condition:

## "he is understanding that I am sick, praise to God" Dina

She described during the interview that when he first knew about her problem, he advised her to seek professional support, but she did not agree. Dina's story suggested that there are certain roles for men in her family. Dina's husband's response to her illness changed over course of time, firstly she thought he expected her to maintain her roles despite her being sick until he saw proof that changed his response towards her illness:

# *"Well, he became so worried and concerned about me, one day I fainted, at the beginning he was a bit"* **Dina**

As per the societal norms, it appeared that Dina's husband acquired a superior position for being the man in the family, giving him the eligibility to be broadly responsible for his wife. Because he has maintained his dominant role in the family, Dina thought it would be socially unacceptable for her to resign or refuse his commands although she had health related problems other than prolapse such as systemic lupus erythematosus. These social norms are further discussed under theme (5).

Lilly in describing her husband's response said that he was patient with her.

## "I feel he is weak; I mean he is patient" Lilly

It felt that she would have acted differently if she thought of her husband as a less patient man. This narrative of Lilly suggests that she mixed up weakness and patience. Her husband's patience was seen as a weakness to Lilly. She said her husband would tell her to seek healthcare support and this suggests he was understanding and concerned about her health and that he did not force her to maintain active sex life in the presence of her illness, yet this was translated as weakness by Lilly. This perception of Lilly was informed by her cultural beliefs about men and a male dominant society like Saudi Arabia. Much of this is explored under theme (5).

"Sometimes he feels sorry for me when he sees me crying and says enough "its ok, I don't want to but you have to go to the hospital", and he takes me to the hospital." Lilly

Lilly's view on her husband's response might be because she has seen different responses from her sisters' husbands or maybe this is related to issues discussed later under the theme of cultural perspectives. Nevertheless, because of her avoidance and her husband's understanding of her condition, Lilly felt that they were growing apart.

"but currently he is on one side and I'm on the other, the lust dies in you I swear, it ends" Lilly

Lilly seemed to feel that they were emotionally separated and that she felt she had no desire for sex. She thought that her husband has coped with this by using his phone most of the time to escape the situation. It felt that she thought this was putting her marriage in danger.

"if he holds his phone he enters another world, maybe I'm the only one who is not into mobile phones. Nowadays all men are addicted to mobile phones, young and old, they drive cars while having their phones in their hands." Lilly

Lilly felt that by using the phone constantly, her husband was absenting himself from the family. It also suggested that she was concerned about her husband meeting other women perhaps on social media.

When Lilly was talking about how her husband coped, she was normalising the use of phones precisely for men and probably comforting herself that there was nothing to worry about. She has specified addiction to using mobile phones only for men suggesting her perceived gender related differences. Lilly also asked me if my husband used his phone frequently, which perhaps further indicates that Lilly was concerned about what her husband might be doing. I replied to her by saying "who doesn't" meaning that the use of mobile phones is very common and provide her with sense of comfort. Looking back at my response to her question, I feel that it could have been oriented towards achieving a deeper understanding through probing further into the issue. However, because of the shared cultural understanding I was concerned about the response of Lilly, and I did not probe into the issue because as a married woman I understand how emotionally disturbing it can be to have such doubts about marital relationship. What was understood here was based on the cultural norms I share with Lilly. This is further discussed under theme (5)

The described responses of the women's husbands to the changes in their intimate relationship might link to the meaning of sex for women which will be explored next.

### 7.4.3.4. Meaning of sex

Despite their involvement in sexual activity, some women felt that sex was limited by their age and gender indicating that it was only important to men. The perception of sex being meaningless for women was commonly discussed by all or most of the participants.

Salwa, one of the older participants, said that she stopped having sex after experiencing prolapse. She then shared her perception of sex that the importance of sex was gender specific saying that it was generally more important to men. She also added that her husband had his reasons for not having sex.

"Intercourse is important for men, but he also has other reasons (Pause) you know advancing in age (Pause)" Salwa

It seemed that Salwa thought that sex was not important to women, or not important to her personally. In terms of her husband, she first said ageing was the reason why he no longer slept with her but elaborated that her husband was impotent and felt that this too was linked to ageing.

"You know, my husband is around 70 years old, and you know with advancing age an individual develops sexual weakness "impotence".

## Salwa

Salwa thought sex was important to men but did not directly say it was important to her husband. She then followed up by stating that her husband has health issues that she thought were related to his age. Salwa's decision to stop having sex would not be easy if her husband did not have his reasons for not having sex. Hence, the decision might be mutual.

In the quote cited, Salwa chose to say "an individual" rather than saying that her husband was impotent. Salwa considered impotence to be a normal part of ageing for men as she also said that advancing in age was one of the reasons for her prolapse. Hence, her narrative about her husband's age and sex could be reflecting her view towards herself that she also was growing old and having a problem that was affecting her sex life.

Zainab said that she no longer wanted sex and that she was sick of it, but she justified her not wanting sex by relating it to her capabilities and her perception that she was an old woman.

# "I mean I don't want to, that's it! I am no longer capable of it, I am an old woman!" Zainab

Zainab referred to herself as an old woman. When Zainab first sought support in the UK she was advised to have a pessary inserted as management, it was rationalised because she was not old, and she accepted the advice. Nevertheless, she still perceived herself to be an old woman and indicated that it was the reason why she did not want sex anymore.

"Because I am old, I am 62 all my children are grown up to men I have grandchildren, of course, I am an old woman!" Zainab She viewed herself as an old woman because of her age and because her children were grown up and she had grandchildren. Her discourse suggests that she perceived that there were certain age and social limits for having an active sex life. Perhaps she was embarrassed by her social image as a woman in her sixties who has grown up children and grandchildren, this is further addressed under theme (5).

Nabeela said a couple of times that she felt she was an old woman; the first time was when she wanted to say that a pessary was not a suitable option because she felt she was an old woman.

## "I said it might fall out and I am an old woman" Nabeela

The second time was when she was talking about her sex life and said that she and her husband no longer had sex as they were both old.

# "Well, he is an old man and I'm an old woman, I'm just concerned about this what is obstructing me." Nabeela

It was not clear on what basis she defined herself as an old woman but gave her indication for referring to her husband as an old man. She felt that he was not interested in women anymore, used an assistive device to walk, and had a "grey beard", and for these reasons, she perceived him to be an old man.

"My husband is old, he no longer seeks women at all, he is very old, very greybeard, he uses a cane, he still walks a bit using a cane but he is really old, praise to God." Nabeela

Her narrative could reflect her own understanding of being old. It is possible that her perception of herself as an old woman could be for similar reasons, in that she was no longer interested in sex and has grey hair. Nabeela also indicated that her mother had a prolapse complaining of symptoms while she was much older than Nabeela, having prolapse meant that she was an old woman because she perceived her mother as an old woman around that time.

Nabeela said that she stopped having sex many years before developing a prolapse possibly for reasons related to her husband and perceived that it was god's will for her to have prolapse.

# "It has been like this 7 or 8 years ago, before my uterus descended and we stopped sleeping together. (Pause), but it's God's will to me to have this, but I'm telling you he is a really old man." Nabeela

Her narrative suggests that she perhaps was relieved that she stopped having sex before having prolapse as it might have posed further problems.

Lilly also shared her views on sex, she thought that sex life affected men. She felt that sex was more important to her husband than to her as he was a man further reflecting Lilly's gender related ideologies.

# "I know that marital relationship affects men yes, but what am I supposed to do?" Lilly

Conversely, maintaining a happy sex life was important to Mai for personal reasons and reasons related to her husband. She personally thought that its importance is relevant to the marital relationship.

"I mean this thing is really important it gives colour to your marital life" Mai

By saying this, Mai might mean that a happy marriage is an indication of a happy sex life, and she wanted her marriage to be stable and happy. The previous section describes Mai's difficulties in relation to this aspect of her life

### Summary

This theme presented the implications of prolapse and its physical manifestation on women's marital relationships. It covered the impact of prolapse on women's body image and revealed that prolapse affects women's perceptions about their body image and women used different words to describe it. This theme also demonstrated how prolapse affected women physically and in terms of their intimate lives. Half of the participants who had active sex lives prior to the experience of prolapse chose to stop or avoid intercourse as a consequence. The response of their husbands to prolapse was also explored under this theme, some men were considerate of what their wives were going through and were understanding of their decision to avoid intercourse. Others responded more forcefully and accepted no excuse to stop intercourse. The views of women on sex were also presented as women who were sexually active even after prolapse highlighted that sex was less important to men and their attempts of maintaining an active sex life were because of their husbands. Women who did not have an active sex life or decided to stop having sex reflected that sex was not important to them as women because their husbands were old and had health issues that have been limiting them from having an active sex life.

# 7.4.4. Theme 4: Healthcare seeking behaviour of women with prolapse and limitations in service provision

### introduction

This theme illustrates the womens' healthcare seeking behaviour. It shows their response to their condition following the identification through women in their contexts that prolapse is a health condition that requires professional support. The theme includes two subthemes that are: factors affecting healthcare seeking behaviour, and limitations identified in the healthcare system. The categories under each subtheme are presented below.

## 7.4.4.1. Factors affecting healthcare seeking behaviour

The majority of women delayed seeking professional support after developing the symptoms despite gaining knowledge from other women around them that prolapse required medical intervention. Under the theme (conceptualisation of prolapse), it was described that women developed self-managing strategies to adapt. The tendency of many women to delay seeking professional support while knowing that they needed it could suggest that the self-managing strategies they developed have been helpful in managing the symptoms, that the symptoms were not worrying them, it could be related to fear or negative past experiences of healthcare, or due to important family responsibilities. Salwa said that her choice for delaying seeking help was because prolapse symptoms were not significantly affecting her:

"I have waited a while, I mean at first it was only bothering me a bit"

Salwa

It is understood for Salwa that the implications of prolapse symptoms are an important factor that determined her healthcare seeking behaviour. Salwa indicated that her son is a physician, and like her understanding of prolapse, his profession did not seem to affect her healthcare seeking behaviour. She has mentioned that he would attend her appointments with her, but she did not say if she has disclosed it to him but said she spoke to her sisters and friends about it. She has waited six months to seek professional help, she added:

"and then, at last, I started to feel that something is coming out and it started to bother me more honestly like 5 or 6 months after" Salwa

Salwa said that the prompt for seeking help was that she started to feel bothered and had a urine infection, she was advised to manage her urine infection issue first.

"The urine problem is the most bothering one, so the doctor told me to end this problem first and has given me antibiotics for it, and about the uterus, she said 2nd or 3rd degree prolapse I don't know what, but I mean uterine prolapse" Salwa

The symptoms of the urinary infections appeared to be more disturbing than the prolapse to Salwa; it is possible that Salwa essentially decided to seek healthcare support because of her recurrent urinary infections otherwise she seemed to be managing (and living with) and controlling her prolapse symptoms.

Zainab was another participant whose children were healthcare professionals, and she also waited a while before seeking help. When Zainab first had her prolapse, she waited until she was in the UK to seek healthcare support with her daughter despite the fact her son was a healthcare professional. Zainab has three sons and only one daughter. This could suggest that Zainab might find it difficult to share her experience with her sons and wait to be with her daughter in the UK to seek help. Moreover, Zainab indicated that noticing the prolapse has been fearful for her and she did not know what to do or where to go. Her lack of knowledge discussed earlier, prolapse has also been a factor that affected her healthcare seeking behaviour and made her dependent on her daughter but not her three sons. Not liking hospitals has been identified as the reason that made Dina and Lilly delay seeking help. Lilly did not seek healthcare support when her symptoms started, even after speaking to her sister who confirmed that she had a "drop". Lilly said this was because she basically did not like hospitals, and it seemed that if it was not for the miscarriage, she might not have sought healthcare support at all.

"I don't like hospitals, nobody does, that's why I did not come when I first had it, but the miscarriage was good it discovered everything, it might be a blessing is disguise/ silver lining as they say" Lilly

She said that nobody liked hospitals, perhaps she meant that it is common for some people not to like hospitals and she was normalising her feelings and her choice for delaying seeking help. Indeed, Lilly had her own categorisation of people's feelings towards healthcare, either people who like or people who dislike hospitals, and she was from the latter category.

## "I am from the type who does not go. Even when I'm pregnant, I don't go until it's time for labour." Lilly

Lilly indicated that she would not go to hospitals when she was pregnant until she entered the stages of labour. This perhaps suggests that she might have high tolerance for pain or there might be some other issues for why she did not like hospitals such as poor past experiences or the gender of the doctor. Lilly then indicated that all her eight deliveries were with a male obstetrician.

"all my deliveries were with male doctors, when you are in pain you don't care if you are being seen by man or woman, but when I was seeing Dr (A) I was a bit shy because I don't feel it's like delivering a baby, so he asks me to expose the area for him to check and I tell him refer me to female doctor" Lilly

Lilly also said that the gender of the physician did not matter at the time of labour as she would be in lots of pain. It could be that she might have concluded from her childbirth experience that she would often be seen by a male physician, and she did not want to agree on that while she would be at a point where she could tolerate pain. Going to the hospital when labour had started could mean that she would be in intolerable pain so she would not have time to think about whether to agree or disagree. A similar issue might also be there in terms of seeking support for prolapse, Lilly did not seek support early in relation to her prolapse possibly because of concerns that she would be seen by a male physician which was concluded from her childbirth experiences. When she sought support, she was originally seen by a male physician and asked to be referred to a female physician as she felt shy. Hence, it can be concluded from Lilly's experience that the gender of a physician is a factor that might in SA determine women's healthcare seeking behaviour.

The past experiences of healthcare were also identified as a factor affecting healthcare seeking behaviour both their own or family members' experiences. Dina was informed by women in her family about treatment options for prolapse. The information Dina's family gave her became part of her knowledge. It appeared that she shaped her decision of healthcare based on the information that women in her family shared with her:

Dina thought hysterectomy was the suitable management plan for her condition based on what she has been told. The knowledge she had however seemed to be insufficient as Dina was further asking about the process of hysterectomy but her questions could also be explained as fear because the knowledge she gained about management approaches, rather than comforting her that there was a solution for her problem, had might have left her scared of approaching healthcare. Dina said she was "scared of something called operation", she had two previous experiences with healthcare where she thought it disadvantaged her health, which was possibly the source of her fear:

"They were all normal, all easy except for the last one it was difficult. I was so sick, the doctor told me don't walk don't move and I listened to her, so I started to have contractions and the girl wasn't yet down to the pelvis yet that's why poor thing she had low oxygen. But in all my pregnancies there was cutting and suturing, with my eldest daughter she is 28 now, I was really sick when I had her because the nurse forgot the gauze inside me and sutured the tear that they made and forgot the gauze inside" **Dina**  The quote above confirms her fear, Dina thought she was given poor advice in her last labour that resulted in her daughter being born with a disability. Another incident was after her first delivery the doctor forgot a gauze inside her uterus following episiotomy. Dina thought she was damaged by healthcare twice and she ended up avoiding seeking healthcare support even at times she was sick and was in need for it. These two past experiences might have caused Dina to have negative expectations from healthcare and she had lost trust and confidence in healthcare professionals.

"I am stubborn I don't like the (Pause), during summer when we were at ... I got so sick there and I said no way that I go to the hospitals there." Dina

Dina referred to herself as stubborn as she would not seek healthcare support even in times of need, particularly for problems in her reproductive area. Therefore, Dina has set few terms or necessities if she decided to approach healthcare:

"I don't like to go to any hospital or any doctor that I am not familiar with, I feel I only want the doctor who I always see, depending if I feel comfortable with him or her, I mean I only go to the doctor who I am comfortable with, you know I told my endocrinologist that please refer me to a gynaecologist that you know and trust and feel comfortable with" **Dina** 

Dina said she preferred seeing doctors who made her feel comfortable or doctor she was familiar with, and this seems that she might wanted to ensure that she was between safe hands and would not be damaged again. Nevertheless, she might have set those terms to make things complex for herself so the easier option would be to simply avoid healthcare. Hence, Dina has chosen to avoid seeking healthcare support for any problem in her reproductive area, not only prolapse, because she did not wish to have any similar incidents.

Aziza also delayed seeking support, she said:

"but I told them that no I will wait a bit not now." Aziza

Aziza said that she did not seek immediate support even after her sister advised her to do so and her reason was that she was reluctant as she did not wish for anybody to see her private parts.

## "I don't know, I swear I was mentally reluctant, I did not want anyone to see me" Aziza

Aziza said she was "mentally reluctant", her choice of words was interesting and could allude that she was aware that her body was in need for help, but her mind was resisting. And by saying "see me", Aziza might mean medical physical assessment and examinations and thus see the prolapse or her private body parts. It felt that she was surrounded by two conflicts, seeking help and be seen, or tolerating symptoms she has and avoid being seen. Her discourse suggest that prolapse was a personal and private issue to her, and physical examinations would mean invading her privacy. She eventually did seek support for primarily managing the UI:

"the urine started to come down one after another, it come and I get in the bathroom and get in the bathroom, and it continued so I came to the hospital here" Aziza

Aziza later spoke about her experience with healthcare for a past shoulder injury, she had to be seen by many doctors until her shoulder was treated. This experience caused Aziza to have negative expectations, or she lost confidence in terms of healthcare as she was concerned that she would have a similar experience of delay resulting in her being reluctant to seek help.

## "I was afraid of being exposed and exposed from doctor to doctor" Aziza

Aziza used the word "exposed" to talk about her concerns of being seen by physicians during examination. Her use of language suggests as discussed earlier that she was rather more concerned about having to undress and show her private body parts specifically that the location of the problem was concerning in terms of being exposed over and over again.

# "You know this problem one would not want to be exposed every time! I mean, you know where it is!" Aziza

Hence, not being physically examined was a priority for Aziza. She had the willingness to tolerate prolapse symptoms until they got intolerable, and she was in urgent need for professional help.

The issue of being exposed was recurring when Aziza eventually decided to seek support after she started to have urinary symptoms, but her discourse suggests that her experience has not been pleasant. It was decided for Aziza to have surgical lifting and she was about to have the surgery but has been delayed for external reasons. Since then, Aziza has been seen by three different doctors, and in her own perception, she was exposed repeatedly.

"I have exposed and was about to do the operations and it was delayed, and them came back to be exposed again." Aziza

Aziza felt that she has been seen by so many doctors so far for her prolapse.

"look how many doctors until now have seen me! That's it I became like charity: exposed to everybody" Aziza

Aziza felt that she was doing the doctors and healthcare professionals a service by allowing them to examine her. She has followed her sentence with a laugh, and she was perhaps being sarcastic about her experience that she was concerned of being seen by doctors due to the sensitivity of her condition but ended up being seen by three or more doctors and feeling exposed. Prolapse seemed to be a personal problem to Aziza and sense of being exposed perhaps reflects the distressing emotions that are originally associated with her showing her body parts, specifically this part of her body, given that she is a religious woman. Given that she has been "exposed" in her past experiences with healthcare, she was concerned that this would happen again but for a more intimate problem.

Mai described that she had been suffering prolapse symptoms for five years but was immersed in her life as a housewife that has been limiting her from seeking help. Mai perhaps felt that her condition required medical intervention, but she seemed to have no time to do so as she was busy looking after her children and maintaining her responsibilities towards them.

"I mean house and duties, every time I thought of going something came up, sometimes it was hospital issues and sometimes personal issues, I have a lot of duties at home with my kids and my daughter's wedding" Mai

Her commitment to family also seemed to be one of the reasons that restricted her from seeking support. She mentioned that she sought support when she started to have urinary symptoms but was pregnant at that time, so she did not receive any management as she was planning to have vaginal reconstruction after having the baby, but she got pregnant again soon after.

"Essentially, the doctor told me an operation since 5 years, she said come after 6 months after delivery I was pregnant back then." Mai

She sought support once while she was pregnant five years ago but did not receive any treatment and was told to comeback after delivery. She did not and despite her illness, she got pregnant three times afterwards and she felt that this was out of her control. Hence, based on Mai's experience, familial responsibilities can be identified as a factor affecting healthcare seeking behaviour.

Family also affected Nabeela and Lujain's healthcare seeking behaviour. Nabeela was following the steps of her mother in terms of how she responded to her illness. Similar to her mother, Nabeela sought the support of traditional medicine practitioner despite indicating that it was not helpful for her mother. She later sought the support of healthcare where she said she was advised to have pessary:

"she told me to reschedule so she can place something inside to hold the uterus" Nabeela

Nabeela was advised to have a pessary as a method for managing her prolapse, the doctor seemed to have explained to her how pessary works as Nabeela said:

"She said she will tie a plastic inside my uterus, and this plastic even might fall out, and if it falls, if I wash up for praying and it falls out I pick it up and through it back inside!" Nabeela

Nabeela did not express a clear understanding of the pessary or how it would be effective, but her comments characterised it as unstable and needing regular attention. It was apparent that Nabeela was unable to make sense of the pessary because it was new to her. She did not seem to accept it and repeatedly indicated that she was extremely sick which might be an indication that she wanted to have a surgical intervention similar to her mother or that she found inserting and using the pessary difficult or unpleasant.

Lujain has mentioned that she was not disturbed by her condition but indicated that her husband was. Her mother informed her about the experiences of her sisters who also have prolapse and did not seek healthcare support for it.

"I don't feel anything else unlike my sisters. They haven't done any operations or anything. (Pause) I mean my older sisters, the eldest has her uterus really descending, the other one I mean is less than the 1st one but more than mine" Lujain

Her eldest sister was greatly affected by prolapse and that she and her husband were sleeping apart, Lujain saw this as a reason why her sister did not seek support.

"She complains of it and says it is really making her sick, but she her husband never even comes to her, I mean she is married and everything, but they sleep in separate rooms, so it doesn't make any difference to her." Lujain

Lujain was saying that her sister did not sleep with her husband, and she perhaps meant that as her sister did not have an active sex life and that it was not important to her seek healthcare support despite being really ill. It can be assumed that seeking healthcare support was important to Lujain because she had an active sex life. She said that her trigger to seek help was to avoid having urinary incontinence, but the actual trigger seems to be her sex life and more about her husband than about herself. Several women asked about my marital status and whether I had children during the interview to further elaborate on their experience of prolapse, particularly when discussing their sex life after developing the condition. Their rationale was they would not feel comfortable speaking about such a sensitive issue to an unmarried young woman. Knowing that I am a married Saudi woman made women to feel comfortable speaking about their experience of prolapse, it was enough to make them feel that there would be a shared understanding between me and them because of the lifeworld we shared as married Saudi women.

"I won't be able to explain if you are not married, I won't be comfortable speaking." Lilly

"you are still a girl "unmarried/virgin" right?" Mai

"You feel unhappy, that's why I wanted to make sure you are married so you understand" Mai

"During intercourse I mean even (Pause) Are you a girl yet or you're married?" Lujain

These participant quotes reflect that these women were not willing to share intimate information about their condition even to unmarried female healthcare professionals. Respectively, this may affect their healthcare seeking behaviour and developing concerns that they will not be understood.

Following disclosing their illness to women in their families, the participants broadly reported that they were advised to seek help. Following seeking help, women identified that they were offered one of three treatment options: hysterectomy, vaginal MESH, or pessaries. None of the women discussed being informed about conservative treatment options with none being offered referral to women's health physiotherapy.

Generally, women were inclined to have surgical interventions, accepting physicians' advice, particularly hysterectomy, to manage their prolapse.

*"Because there are lots of people, they say they have done an operation but did not remove the uterus, but it hangs just for 5 years, 5* 

years and it comes out again. I don't want it like this, I mean now I do the operation and then wait to do it again? I really don't want this, because I know someone who has done the operation without removing the uterus and it came out again." **Dina** 

"it's better to have it removed. I have been suffering for years now." Lilly

"But it's better for me to remove it, because if I lift it, it might go down again, so it is better to remove the uterus she said so you are in ease/rest afterwards." Lujain

The participants demands and responses for alternative treatment options may reflect the lack of knowledge about other treatment methods that might be relevant to their lack of knowledge about prolapse. It could also imply that women wanted to put an end to or solve their problem.

## 7.4.4.2. Limitations in the healthcare system

Participants had waited between 6 months to six years to seek help. However, all eight women eventually approached healthcare professionals for advice about managing the prolapse but identified important professional and practical limitations in the current healthcare system, which included:

- Delay or difficulties in accessing a specialist doctor.
- Difficulty with the appointment booking system.
- Geographical issues due to the specialist hospitals with a professional urogyneacologist being located significant distances from their homes.
- Communication issues for example that the physician did not fully explain the condition
- Failure to acknowledge medical mistakes and lack of compassion which may reflect lack of trust.

These issues will be explored in more detail, it is important to note that many of the women experienced these limitations and all impacted on their healthcare experience.

7.4.4.2.1. Delay or difficulties in accessing a specialist doctor:

Upon decision to approach healthcare, one common issue was reported across women which was being delayed for accessing specialist doctor for hospital related constraints. For some women the delay meant worsening of the symptoms or in the size of the prolapse:

"Now few days ago I was looking and it became this big (fist), the uterus is descending, now the urine sometimes when I am sitting, sitting like this, I just stand up and I see myself all wet, without me feeling of course" Aziza

Aziza said being delayed for more than four months caused her symptoms to regress over time, particularly her urinary symptoms. Lilly said that she was seen by male physician first and asked to be referred to a female physician. But the process of referral took a long time, and her access to the specialist doctor was delayed many times.

"he referred me to Dr, (I) whom I have waited for months and never seen, (Pause) moving from one appointment to another and she never comes or throws me to the residents list" Lilly

By saying "throw", it felt that Lilly might have thought that her problem was being underestimated by the doctor or that her problem was perceived less serious to be seen by a specialist doctor. Waiting to be seen by a specialist doctor for some time has made Lilly to feel that her symptoms got further worse. Lilly felt she disadvantaged by her late access to the female specialist doctor given the progression of symptoms, she had the option to manage the condition with a male doctor, but she chose to be seen by the specialist female doctor; however, it felt that Lilly was blaming healthcare for the regression of her condition. Indeed, instead of talking about the symptoms she had as effect of prolapse, Lilly was speaking of them as a result of her late access to the specialist female doctor.

7.4.4.2.2. Difficulty with the appointment booking system:

This issue of delayed access has also been addressed by Nabeela, she said:

"Even making the appointments here is hard, my daughters have been looking how to make appointments and they said everything is by using the internet, and they made me the appointment through the internet and I find that the appointment is in a year and a half!!" Nabeela

Nabeela indicated that she faced difficulty in making appointments firstly because it is done by using the internet, secondly because she was unable to find any recent appointments. Her dependence on her daughter to make the appointments could suggest that Nabeela had limited digital literacy which perhaps explains why she perceived the process to be difficult for herself.

7.4.4.2.3. Geographical issues due to the specialist hospitals with a professional urogyneacologist being located significant distances from their homes:

Difficulty in access was also noted when Nabeela spoke about going to the hospital, she was depending on her son to take her to hospital which she thought was far from her home.

"I swear it's a long-distance driving from my home to the hospital and the way back but you guys never believe me when I say that" Nabeela

She also added:

*"My son always tells me it too far and long drive just to drop me here for half an hour appointment"* **Nabeela** 

Nabeela seemed unable to make the appointments by herself, could not find any recent appointments, and depended on her son for transportation. These factors could possibly explain her behaviour when she attended the clinic with no scheduled appointment. This lack of engagement with modern technology could underpin why she sought support of traditional medicine and then went to a clinic that was close to her house where she was given medications for relieving pain, which was not helpful but perhaps triggered her to seek support at a hospital.

7.4.4.2.4. Communication issues:

Nabeela said that following examination the doctor told her that there was nothing wrong with her.

"about a year ago, I swear I came here and I had an appointment with Dr, (I). I came and said I have this and that, and she said she needs to check me down there, she checked and said nothing is wrong with

you" Nabeela

She felt that what the doctor told was contrasted to how ill she perceived herself to be and she did not seem to be happy about it as she said:

"Anyhow, when I came for the re appointment, they wrote that I was sick, I'm not just sick I'm in so much pain, even sitting I can't sit! I feel my uterus is extremely descending and sometimes I see blood coming out with it." Nabeela

She possibly felt that her problem was being underestimated by the doctor which perhaps would give her less priority in terms of appointment or the care she would receive.

Salwa said that she was advised to have a hysteroscopy to further confirm the diagnosis of prolapse. It is unknown on which bases the physician advised her to do so but she refused to do it as she was concerned about the results. Therefore, she said that she decided to seek consultation of another physician. During the interview, when Salwa was asked about what knowledge she has about prolapse given that she sought support, she answered that she knew nothing about it. she further added:

## "I haven't asked her anything nor did she tell me anything." Salwa

In addition, she mentioned that her son who is a physician often attend her medical appointments with her. Hence, the doctors discuss her condition with her sons instead of her. This may reflect the issue of lack of sufficient communication with patients whose children are HCP. Salwa might have other concerns that she was not able to discuss with physician and the fear she was experiencing as a result of

being advised to have hysteroscopy suggests that the doctor did not explain it to her; thus, her needs of healthcare have not been met.

7.4.4.2.5. Failure to acknowledge medical mistakes and lack of compassion which may reflect lack of trust:

Zainab also have indicated that her experience of healthcare did not meet her expectations at first rather she was disadvantaged, she said:

"the woman in the poly clinic when she placed it I had bleeding with it, I don't know what is wrong with this woman, maybe she wants me to come a lot to see her" Zainab

Zainab narrated her experience with healthcare in Saudi Arabia, she said she started to go to a polyclinic that was close to her house. Broadly, polyclinics in Saudi Arabia are private clinics that offer paid healthcare services. Zainab sought support in order to change her pessary, and she did not mention the doctor's response to it or whether she suggested different approach of management. Nevertheless, Zainab's experience at the polyclinic was unpleasant to her. When she spoke to the doctor, the doctor asked to do some tests and check-ups. Zainab seemed unhappy when talking about her experience at the polyclinic. In the UK, when Zainab felt pain and perceived that the pessary was misfitted, her doctor there owned the responsibility of her mistake and acknowledged that it was her fault. However, in Saudi Arabia at the private clinic, the doctor's response was different than the response she seen from her doctor in the UK.

Zainab did not say whether she has done further tests to investigate what was going on. As it was a private clinic, doing tests meant that Zainab would pay for those tests and also pay for each visit, this could explain why she speculated the doctor's intentions as Zainab thought that the doctor was purposely misplacing the pessary so she would visit her often and perhaps she would make money out of each visit.

## Summary

This theme demonstrated the healthcare seeking behaviour of women with prolapse. It showed that there are certain barriers and triggers that affects their

choice in terms of delaying seeking professional support or ask for help as soon as identifying that prolapse is a condition require medical or healthcare intervention. After seeking professional help, women have identified limitations in healthcare system, these were also presented under this theme.

# 7.4.5. Theme 5: The role of Saudi Arabian culture in shaping the experience of prolapse

## Introduction

This theme provides a greater understanding of the other four themes presented above. The four themes presented earlier were generated following the interpretation of participants' narratives. It was initially concluded that the Saudi Arabian culture was an overarching theme that explains the generated four themes; thus, it was decided not to present it as a separate theme. However, this was a major finding from the data as culture indeed greatly informed the womens' experience with prolapse. This was one of the main contributions of the study findings to the current literature about the experience of prolapse. Thus, it was deemed suitable to address culture as a separate theme.

women did not speak directly of culture in relation to their experience, but I understood it as a young married Saudi woman sharing the culture with these eight women. The immersion in the analytical process permitted by the attempts of IPA followed by RTA that was eventually undertaken to analyse study data revealed that there were further cultural issues that the women did not directly speak of. These issues were evident to me as a researcher following close engagement with their narratives and because I essentially shared the cultural background with study participants, there was a shared understanding between me and them. This theme illustrates the role of Saudi Arabian culture, that I could read between the lines of their interview transcripts, in shaping the experience of women with prolapse. It includes four subthemes: family dynamics and womens' relationships, gender ideologies and roles of women, cultural beliefs and sensitivity of prolapse, and the Islamic religion perspectives. Each of these subthemes are presented separately below.

### 7.4.5.1. Family dynamics and women's relationships

All study participants indicated that they have disclosed their illness to at least one woman in their families. They had no knowledge about prolapse and indicated that they were afraid and anxious about their condition but sought support of women in their families rather than seeking professional help. They had willingness to share the experience of a condition related to sexual health with women in their families despite that such issues are not often outspoken in Saudi Arabia. This reflected that sharing private information with other women is socially accepted. None of the women reported feeling concerned about being judged for discussing prolapse with women in her family, rather it was a safe place where women could share their concerns and look for solutions. Women in their families openly shared their past experiences with prolapse with them and provided them with various forms of support as presented in theme (2).

Nabeela, Salwa, and Zainab have spoken about the involvement of their children in their healthcare plan. When Nabeela spoke about her experience of healthcare, the issue of dependency on children was brought up. Nabeela said she depended on her daughters to make her appointments and on her son to take her to hospital. This demonstrated the familial bond between them as she as a parent was somehow dependant on her children. This issue is culturally common in Saudi Arabia, children after growing up become carers for their aging parents. It is viewed as an opportunity for children to honour their parents and pay their parents back the care they were provided when they were young children. Nabeela was also involved in her own mother's experience and has been there for her when she sought professional support. She has closely observed her mother when she had prolapse and constantly compared her own experience to her mother's.

When introducing herself, Salwa said that she was a medical student who did not continue her education, but her children did so on her behalf. This possibly implies that their success in life is perceived as her own success which could demonstrate the family dynamics in Saudi Arabia and the responsibilities parents have towards their children and the other way round. Some parents, particularly mothers, often give up their education by choice to look after their families, and after their children grow up, they will have to look after their parents. And this was the case with Salwa, when she sought healthcare support, her son and daughter would take her to hospital and be closely involved in her condition.

Dina and Lilly indicated that their daughters who are above 20 years old are still living with them and they as parents provided care for them through looking after their needs. This might be unusual in westernised societies, but in Saudi Arabia it is common for children to stay with their parents until they get married and move to another house with husband or wife. Nevertheless, this further demonstrated the family dynamics in Saudi Arabia and explain the bond that ties family members together and explain why women chose to share their experience particularly with women in their close family.

### 7.4.5.2. Gender ideologies and roles of women

This subtheme was recurrent across study participants experiences. Women spoke about certain issues that reflected gender ideologies but were accepting those issues because they were part of their culture. The first gender ideology was that there were certain gender specific roles entitled for men and women. Women in this study indicated that they were housewives except for Aziza who was a history teacher. Salwa said she was a medical student but chose not to complete her education after getting married. Mai and Lilly said they had bachelor's degrees in teaching but chose not to work. The seven participants, except Aziza, have identified themselves as housewives when asked to introduce themselves in the interviews. Respectively, women's roles were to be responsible of household duties, looking after children, cooking and cleaning, also holding receptions for wider family such as in the case of Dina. Because it was part of their specific roles, Dina and Lilly mentioned that they were overly consumed by housework.

Reproduction was another issue that appeared as a part of women's responsibilities. Women in this study had up to 11 children and some reported that frequent childbirth have caused them to develop prolapse but it did not seem to be under their choice rather it was a decision that society has already made for them. Therefore, Mai for example indicated that it was not her personal decision. Dina and Lilly thought spacing between children was an issue but did not perceive

conceiving eight or eleven times to be disadvantageous to their health. They felt it was part of their roles as women.

Similar to women, it was understood from women in this study that men also appeared to have certain gender specific roles. For being a man, it appeared that Dina's husband acquired a superior position in the family, giving him the eligibility to be broadly responsible for his wife. Because he has maintained his dominant role in the family, Dina thought it would be unacceptable for her to resign or refuse his commands in terms of doing housework although she has health related problems other than prolapse. Dina indicated that her husband did not mind her maintaining her roles within the family despite her complaining of prolapse symptoms, but later on he became understanding of her condition asking her to rest. Her decision to take control or take an "open vacation" was perhaps following his approval of her illness. She further indicated that she was not able to have intercourse and has advised her husband to seek another wife. Telling her husband to seek another wife might be a form of controlling the feelings of guilt that resulted from her not having intimate feeling for her husband.

Lujain said that her husband being bothered during intercourse was problematic to her despite that he comforted her many times by saying that it was not problematic to him. This might be reflective of the dominant position men socially acquire in a marital relationship in Saudi Arabia, and the subsequent submissive role women obtain. Indeed, Lujain seemed to believe that the ability to cope with challenging circumstances was also determined by gender.

# "I mean we are fine with things, we cope, and they get bored that it is not easy." Lujain

She was somehow concerned that her husband would have had enough with being bothered during sex. Her belief also suggested that she might be bothered but, for being a woman, she coped with her condition. She in fact asserted few times during the interview that she had willingness to live with prolapse. The assumption Lujain had was possibly based on what she has seen in her sisters that demonstrate such culturally embedded issues about the gender related differences between men and women. Lujain was the youngest of her sisters and the stories of her older sisters with prolapse, as discussed above, have influenced her own experience. Her eldest sister was coping with the debilitating symptoms of prolapse but chose not to seek healthcare support because her husband was not sleeping with her, and her second sister has also coped but for different reasons.

"her husband doesn't like to take her or bring her anywhere, thanks to god my husband I mean has provided me with means of comfort, he brought me a maid, (Pause) he is blissing me I mean" Lujain

Lujain saw that she has been privileged that her husband has provided her with means of comfort that made her life easy. She thought that her sister's husband responsibility as a man was to provide her with a housemaid and take her sister to seek healthcare support when she felt sick. Respectively, her sister as a woman had to cope and live with the resources that her husband had provided her with and self-manage her health problems.

"That poor she started to use medications and use mercurochrome until the wound was about to become rotten/ infected" Lujain

But the issue here seems that it was not the act of taking her to hospital, but her husband perhaps did not approve or gave her his consent to seek help. Acquiring a superior position means that the approval of men is necessary in terms of healthcare related decisions and giving agency to women in their families in Saudi Arabia. Lujain's husband had comforted her by giving her agency to choose what to do with her body.

"I mean even this what is coming out of me he did not complain, he said yes it bothers me but it's up to you, it's fine with me I have no problem with it, it bothers me but it's fine. (Pause) He has given me freedom to choose what is more comfortable to me" Lujain

But this perhaps was contrary to her cultural beliefs as despite comforting her and telling her he did not mind; Lujain was still concerned that he would get bored because of difficulty in intercourse possibly because her perspective that men are dominant to women. Mai's overall experience with prolapse and subsequent symptoms reflected certain cultural and religious issues. When she spoke about her close and wide family, and the involvement of her in laws in her personal decisions, it demonstrated the family dynamics that are common in Saudi Arabia. To begin with, Mai said that she rejected a job offer as she had to maintain her responsibilities towards her close family. It felt that she had to compromise her career because she was a woman, and perhaps it was not important to her to work as her husband was. This is rooted in the cultural traditions in Saudi Arabia that women are ought to stay home and look after family, while men are expected to have a stable job and provide family with resources. Respectively, women are financially dependent on men. Indeed, Mai indicated that she had to seek support at governmental hospitals because there has been a change in their financial status because her husband bought a new house.

Being dependant on her husband financially might have made Mai feel subordinate in the relationship, this perhaps was acceptable to Mai as it was culturally common. She appeared to be living with the available resources without being demanding, indeed, Mai said that their car was high and getting in and out of the car made her feel pain in her uterus, but it did not seem that she has spoken to her husband about it. Moreover, her husband also pointed out to her that she was "wide", and she was not saddened by the way he said it rather she was concerned about him that he was not sexually happy or satisfied.

Mai also spoke about religiously prohibited issue when she was talking about her husband's response towards her feeling vaginally wide. Mai said that her husband would ask her to have anal sex, and she sounded surprised when telling me that. Mai perhaps was aware that this is something religiously unacceptable, indeed, it has been said in the Islamic religious texts that couples who have anal sex are cursed by God. Yet, her husband asked her for it as he was unpleased with vaginal sex, and it seemed that she was accepting it as she perhaps had no other option.

As Salwa was speaking about the implication of prolapse on her sex life, she indicated that she stopped having sex since she had the problem because she felt "bothered". She further said that her husband did not mind because he already had his own barriers, but she also pointed out that sex was important for men. This might be relevant to the common gender ideologies that are informed by her

cultural background. Sexual capabilities of men and women are constantly compared, and it is often concluded that capabilities of men are greater than women's; and therefore, some assume that men are allowed to have up to four wives for this reason, but Salwa's husband had some health problems that limited him from having sex, hence this might have contradicted her perception.

The concept of "men power" emerged a couple of times during the interview with Zainab, the first time was when Zainab was narrating her experience at the polyclinic, how ill she felt after she had her pessary changed there and the complications she had afterwards. Zainab indicated that she has a husband while narrating how these symptoms affected her, she considered that the smell and discharge she had was bothering not to her but to her husband as they have an active sex life and it seemed that this was concerning her.

Zainab's experience suggested that there was power imbalance in her marital relationship. This was evident when she spoke about her reasons for not wanting sex but eventually having to tolerate it as her husband wanted sex. The reasons for which Zainab had to tolerate sex was because she was concerned that her husband would seek another wife. This thought is again rooted in the cultural influence on gender ideologies. The religion of Islam allows men to seek up to four wives for different purposes such having more children or when wife is no longer able to fulfil husband's sexual needs such as in Zainab's case. She felt that her husband wanted an active sex life and if she did not agree, she was anxious he would seek another wife. However, her concerns did not seem to be related to herself or their relationship, rather she was concerned about her children despite them all being adult. Perhaps Zainab's concerns were about inheritance, if her husband got married all his inheritance would be divided between the old family: her and her children, and the new family. Clearly, Zainab did not wish for that to happen; hence, she tolerated sex despite the occasional bleeding she had after wards.

Men power also emerged when Zainab was talking about her husband's health, she said:

"Otherwise, he is older than me he is 70 or more than 70 years old, but mashallah he is healthy and well." Zainab Here Zainab was perhaps rationalising why he wanted to have sex and she did not. In addition to perceiving herself to be an old woman, Zainab had a health problem: prolapse. She indicated that her husband was older than her but was healthy. There is a cultural view towards men that they are stronger than women and able to have an active sex life until a very old age, perhaps age was a factor the Zainab thought would limit women from having an active sex life but not men.

Lilly also shared her views on men. To begin with, she thought that sex life affected men and did not share her view about women. She could perhaps mean that she felt that sex was more important to her husband than to her as he was the man further reflecting Lilly's gender related ideologies.

# "I know that marital relationship affects men yes, but what am I supposed to do?" Lilly

But it felt that she did not think that it affected her husband much, her husband's patience was interpretated as weakness.

## "I don't know but my husband is weak, (Pause) there are no weak men" Lilly

It sounded as if his behaviour was not manly enough in her perception, and she might have expected a different response. The cultural view towards men is that they are controlling and dominating as she said "there are no weak men" and it perhaps made Lilly expect that she would see less understanding and more forceful response. This common view was further evident when Lilly said:

"The lady who was doing my urodynamics was asking me about my marital relationship as well, I told her it's all trash, she said believe me its not because of this thing you have, men are the reason" Lilly

Lilly said she was asked about her sex life during the urodynamics assessment probably by the nurse and she answered her by saying "it's all trash" and her metaphor suggests that she was extremely unhappy with her sex life. And the nurse on her behalf told her that the reason for her disturbed sex life was her husband, not her prolapse and Lilly seemed to agree with her as she said:

# "I told her yes you are right (Laugh), they always rain on your parade she made me laugh" Lilly

There seemed to be an image or perception of a strong man that Lilly perhaps thought that her husband was the opposite of it. Lilly mentioned a couple of times that her husband was understanding and supportive of her condition, and he allowed her to be seen by a male physician so she would not have to wait until she was seen by a female physician. The response of Lilly's husband can be described as culturally unique in a society that enforced male superiority. Based on the experiences of other women in this study and their narratives, it can be seen that such responses from womens' husbands were not common.

Lilly highlighted another issue that is concerning to women in her interview. She spoke about her husband being detached from the real world when using his mobile phone, and it has been presented in theme (3) that it has caused her some level of anxiety that her husband is meeting other women. This is perhaps relevant to the fact that men are allowed more than one wife which might make women always anxious and threatened when their husbands are unavailable.

## 7.4.5.3. Cultural beliefs and sensitivity of prolapse

The potential sensitivity of prolapse or sexual related health conditions in Saudi Arabia was evident in the experiences of women. The numbers of childbirths as reported by study participants in this study ranged between two to eleven births. Yet women lacked knowledge about prolapse suggesting that they received no information about prolapse neither they were asked about potential prolapse symptoms or given Kegel exercises in the postnatal check-ups.

Women in this study did not appear comfortable speaking about the sexual implications of prolapse without knowing my marital status at first. Lilly, Lujain, and Mai indicated that knowing that I am married has made it easier for them to openly discuss the sexual issues they were experiencing. Additionally, the gender of physician has been reported as a barrier to seek help. This reflects that cultural sensitivity of prolapse that makes difficult to be disclose to healthcare professionals and shaping the healthcare seeking behaviour of women.

Women during the interviews shared information that can be viewed as private or sensitive from the cultural perspective. For example, Mai spoke about her husband asking her for anal sex which I as a Muslim Saudi women knew it was prohibited. Lujain stated that her sister's husband no longer slept with her sister; thus, she felt that managing her prolapse was no longer necessary. Lilly said her husband was constantly using mobile phone which respectively made him cope with her avoiding sex, and she further asked if my husband was also on the mobile phone all the time. Because I was aware of the privacy and cultural sensitivity of these issue, I did not have clear boundaries about how much to ask and when to stop. I was concerned about womens' responses in both cases. The shared cultural perspective somehow limited me from further probing but it provided me with opportunity to interpret their narratives and understand what they were saying, I was able to make sense of their sense making.

Women shared their experience of prolapse with other women in their families. They spoke to them about the symptoms they were experiencing such as the bulge, the heaviness, the pain, and the urinary symptoms. Women did not mention if they also shared the implication of prolapse on their intimate lives with their family except for Mai. She specifically mentioned that she did not share the impact of prolapse on her sex life with her sister or anyone else because this was a private issue. From a cultural perspective, the intimate relationship between a man and a woman in Saudi Arabia is a sacred relationship. It should not be shared or discussed with anyone other than the man and woman involved. Thus, it can be understood that women did not share it with other women in their families.

Zainab and Salwa indicated that they both have sons who are healthcare professionals, but it did not seem to affect their healthcare seeking behaviour. This may suggest that they found it difficult to discuss their health with their sons, which is acceptable with the cultural norms in Saudi Arabia that views sexual related health issue to be taboo to discuss with males apart from husband as they cannot be kept hidden from him.

## 7.4.5.4. Islamic religion perspectives

Aziza has used the words "expose" and "hide" interchangeably. She did not wish to be exposed to physicians during assessment, and also wanted to hide that she had no bladder control. There seemed to be an impulse to cover herself physically and morally that was perhaps rooted in Aziza's religious belief. Aziza referred to mankind as "son of Adam", from a religious perspective Adam was the first human God created. It was indicated in the Islamic holy book that God ordered Adam to cover his private body parts when he was sent to earth from heaven. This seemed to be the natural order of things to Aziza, she perhaps thought she was obligated to keep her private body parts covered as she was a descendant of Adam, which was upholding her from seeking herself and being examined.

Islam asserts on the necessity for women to cover their bodies. The obedience of women to this rule correlates with how strong their religious beliefs are. Therefore, it is acceptable for some women to expose their body parts, especially private areas, for various purposes relevant to healthcare, while other women find it difficult particularly if they had to do it many times because it goes against their belief. Aziza's discourse suggested that she was a religious woman with strong beliefs, it might be less hard for her if she had the desired support from her first visit to healthcare but moving between multiple physicians perhaps contradicted her belief on the urge to cover her private parts repeatedly.

In terms of cover self morally, Aziza said that "son of Adam is veiled" in the context of hiding her lack of bladder control. She perhaps meant that all mankind has different issues that are supposed to be kept hidden as Islam advises people not to talk negatively about themselves or mention their flaws in front one another even if it was in front of close friends, this includes physical issues such as in Aziza's case and also some wider issues.

There is a common religious belief that anything happens to one has been written for him/ her even before he/ she was born; and therefore, one should never fight back destiny or question why it happened. Indeed, difficult conditions are perceived as testing method for one's patience and strong beliefs. Aziza considered that she was destined to have prolapse and she chose to accept what happened to her so far, including the cancelled operations, as her fate which might justify her passive response. When Aziza rationalised prolapse as a result of pelvic weakness, looking at it as God's will was also emerging as it felt that she has accepted this as part of aging because she saw this as relevant to human life cycle.

Religion also emerged from Mai's narrative, particularly when she spoke about agency. She believed that her pregnancy was under the will of God. This perspective is relevant to the concept of destiny in Islam which implies whatever happens to one was already written for them before they were born. Even when Mai was talking about the effects of her urinary symptoms, she seemed to believe that it was God's will, and she was destined to have this.

Nabeela's religious beliefs also emerged as a theme during the interview few times. She mentioned few causes for having prolapse but then said that it was God's will for her to experience it. She appeared to accept prolapse as if she was destined to have and perhaps being Muslim meant she was obligated to accept life events: happy or sad as fate and was religiously prohibited to question why it happened or link it directly to other reasons.

Women in this study perceived aging to be a causing factor for prolapse, some described themselves to be "old" despite their age ranged between 49 to 62. Their Islamic religious beliefs perhaps can explain why they perceived themselves to be ageing. There is a saying by prophet Muhammed that indicated that mean age for his followers is between 60 to 70 and can be less or more. Thus, approaching the age of sixty might have meant for these women that they were ageing and approaching the end of their lives. Aziza in fact said that "this is son of Adam, and this is his age", and it did reveal her religious perspective on ageing.

Lujain is 62 years old and she said she looks after herself and therefore looks younger than her actual age. She did not specifically mention that she was ageing but said that she has prolapse possibly because of ageing. This is an indication that approaching the age of sixty in Saudi Arabia is equivalent to ageing even if one attempts to maintain healthy lifestyle because it is embedded in their religious beliefs.

#### Summary

This theme provided an overview of the role of Saudi Arabian culture in shaping the experience of prolapse. The implication of culture was evident in women's discourses provided in the themes above, but women also spoke about culturally specific issues that could only be addressed by researcher sharing the cultural background with study participants and immersed in their narratives. The family dynamics, gender ideologies, apparent cultural sensitivity of prolapse in Saudi Arabia, and women's religious perspectives have informed their overall experience and their healthcare seeking behaviour.

# 7.5. Chapter summary

This chapter outlined the study findings. It revealed that five themes were generated following the analysis of study data that are: conceptualisation of prolapse, social support provided by family, prolapse and implication on marital relationship, healthcare seeking behaviour and limitations identified in service provision, and the role of Saudi Arabian culture in shaping the experience of prolapse.

The analysis of study data using reflexive thematic analysis revealed that being surrounded by similar cultural background and social norms resulted in these women having a shared experience of prolapse. Women's narratives at first glance may suggest that their experiences are personal and different, but immersion in study data and engagement with participants discourses during analysis revealed the shared aspects of the experience. This may not have been permitted if I also did not share the cultural background with study participants. The generated themes have been explored in depth in this chapter. The next chapter discusses the findings in relation to lifeworld theory and existing literature about the experience of prolapse.

# 8. Chapter Eight: Discussion of Findings

# 8.1.Introduction

The aim of this thesis was to explore the lived experience of prolapse from the perspectives of Saudi women around the age of menopause. This chapter will explain and discuss the findings in order to answer the research question. Moreover, this chapter restates the findings of the study, compares these to existing literature and seeks to interpret whether and how the findings of the study provide a better understanding of the experience of women with prolapse in Saudi Arabia.

A discussion of the culture and the social norms in Saudi Arabia has been presented in chapter (2). It was considered that the social norms in Saudi Arabia would have an inevitable impact on shaping the lives of women. Hence, the aim of the thesis was to explore how Saudi Arabian women perceive their experience of prolapse and to understand the impact of Saudi culture on their experience of a condition that is socially hidden and culturally sensitive. A qualitative interpretivist approach was adopted to answer the research question, data were analysed using RTA. The results were presented from the perspective of the individuals (see appendix G) as well as identifying shared or common themes (chapter 7). My role as a researcher was to highlight the unique experience but also to identify the shared meaning across the participants despite the individuality of the experience in order to understand what it is like to experience prolapse in Saudi Arabia. This was facilitated by the cultural background that my study participants and I have in common. The women's narratives reflected their relatedness to the world in which they live in and particularly how this influences their understanding and how they make sense of their experience in relation to their world. Reflecting on theme (5)in the previous chapter, it demonstrated the role of Saudi Arabian culture in shaping the experience of prolapse, it is considered that the lifeworld theory may be an appropriate theoretical perspective from which to consider the findings of this study.

In this chapter, the experience of prolapse will be analysed from a philosophical perspective, specifically the lifeworld framework (Husserl 1970). According to Husserl (1970), the lifeworld includes individuals' everyday experiences of self, body, relationships, feelings, beliefs, thoughts, and language (Ashworth 2003). Exploring the lifeworld of these women, their perceptions, relationships, beliefs, cultural issues and health care experiences are necessary to understand how they develop shared meaning, choice, and a voice in their worlds. All of the aspects of the lifeworld as described by Ashworth (2016) – these being embodiment, sociality, project, selfhood, temporality, spatiality, discourse, and moodedness - can be linked to the shared themes generated. This will be discussed in the next section.

# 8.2.The lifeworld

Husserl (1970) defined the lifeworld as the meaningful world that one lives and experiences, where one encounters their sense of self, embodiment, relations with others, spatiality, temporality, projects, discourse, and mood (Ashworth 2016). Lifeworld can be viewed as a cultural environment where one interprets, communicates, and socially engages in multiple spheres. Todres et al. (2007) described the lifeworld as 'a world that appears meaningfully to consciousness in its qualitative, flowing givenness; not an objective world "out there", but a humanly relational world'. As human beings, it is our nature to be there in the world, located and observable in our relations in a meaningful context (Reid et al. 2005).

The lifeworld framework was originally introduced by Husserl, and it is based on the phenomenological concept of naturalistic attitude. Husserl (1970) viewed natural attitude as the complete immersion in one's experience of being part of existence and the everyday world, without reflecting on what the experience means. This theory is often adopted by phenomenological researchers because it allows them to free themselves from the past and theoretical knowledge they acquire and dwell on the immanent experience to encounter 'the things themselves' in their appearance (Finlay 2011). It is aimed at understanding what would it be like for me or someone else to experience this situation. This epistemological view is usually employed to answer questions about knowledge and how it is possible to gain access to, and understand, other humans' experiences.

Husserl's phenomenology is based on the experience of internal subjective world, we cannot speak of something we did not experience as we as humans are selfevident, once we know ourselves; we will be able to construct the outer world. Phenomenology as a method examines the context of our mind through suspending the outer world, it is about examining ourselves rather than the outer world. Phenomenology was based on the concept of bracketing to understand the experience of a phenomenon, but later on Husserl challenged this and acknowledged that we share an intimate relationship with our world. The lifeworld theory recognises that our consciousness is operated on in a world of meanings that are culturally, socially, and historically constructed (Husserl 1970). This world is personal to me, but it is shared between me and the women I am trying to understand their experience.

The concept of the lifeworld acknowledges that individuals live within a world that they understand, this world consists of their internal experience; their bodies, perceptions, relationships with others and the external world within which they live and interact (Ashworth 2003). This means that the participant cannot separate themselves from the world in which they live, nor can the world in which they live be separated from themselves, Heidegger and Jaeger (1962) had described this concept as "being" in the world. In terms of the findings of this study, the concept of being in the world was apparent in womens' experience with prolapse, and it was reflected in the themes generated from their narratives.

Merleau-Ponty emphasised that human experiences are only meaningful to mind if not detached from the body, as 'man is in the world, and only in the world does he know himself' (Merleau-Ponty 1962,1995, p.xi). Moreover, the relationship between the body, self, and also the world is then interwoven in a world that they live in. Respectively, according to Todres et al. (2007), belonging to a common or shared world would result in similarities and differences in actions and behaviours. Thus, the importance of looking at my participants individual and shared experiences. In addition, our past experiences as human beings also have an inevitable impact on shaping our forthcoming experiences as according to Koselleck and Gadamer (1997) we live in the world as 'historical creatures'. It has been proposed in chapter (2) that the lives of women in Saudi Arabia have been governed by certain cultural and religious rules that were disadvantageous to them such as driving ban and male guardianship law. These restrictions were however lifted in 2017 but women in my study did not seem to be affected by this. Some were still complaining of depending on sons for transportation or needing the approval of husbands to seek support. Based on this perspective, the lifeworld can also be understood as a world of multiple possible meanings, a never-ending process, the life-world fractions such as language, temporality, history, and culture, are important tools that aids in understanding the world one lives in. The complexity and interpretation involved in the lifeworld mean that understandings can be dynamic, meanings can be complex and often multiple. As a result, meaning making is never categorical and often evolves based on the multiple influences from the lifeworld.

In aiming to explore the experience of pelvic organ prolapse from the perspectives of Saudi women, they share a similar lifeworld to myself specifically, that I am a married woman with children living and working within the Kingdom of Saudi Arabia, this has I believe enabled a deeper shared understanding. Moreover, this study is conducted under an interpretivist paradigm that acknowledges that a person's narratives are a result of their relatedness to the world they live in. Last but not least, this study started out as an IPA study thus was guided by IPA framework which is rooted in phenomenology (Smith 2012). IPA was not adopted as a methodological approach in this study as it was found that it was not suitable, and the analytical approach was changed to RTA but this theory fits well with my epistemological stance that has been presented in chapter (4).

### 8.2.1. Justifying the choice of lifeworld theory

During the interviews, women shared their rich and deep stories under the experience of pelvic organ prolapse. Their stories allowed me access into their worlds and understand what it feels like to be a married Saudi woman around the age of menopause living with prolapse. Women went beyond solely speaking about the experience and talked about some central issues in their lives that had informed

their thinking in relation to pelvic organ prolapse, shaped by their life world, such as their religious beliefs, cultural gender role norms, their roles in the family that impacted their identity and relationships, in addition to living and coping with prolapse and their healthcare seeking behaviour.

The findings of this study reported the unique culture of Saudi Arabia, and considering the theory to be used here, lifeworld is a westernised theory developed by a western philosopher, yet it does go some way to explain the experience of prolapse in Saudi Arabia. This was facilitated by my cultural perspective; I was able to see the impact of culture on their experience. I share the lifeworld with these eight women. In addition, I am a married woman who have experienced childbirth, and women during the interviews asked me questions about certain cultural issues and my answers made them comfortable in speaking up to me. However, certain elements of the lifeworld theory "particularly discourse" were not fully used to explain the experience of prolapse. This is because the womens' narratives were translated and exploring the use of language may not be sufficiently achievable on translated texts (see chapter 6).

Discussing my participants' experiences within the framework of the lifeworld is supported by consideration of the lifeworld fractions, discussed in the following section, that appear to resonate with the participants stories. These fractions are not distinct and overlap when trying to understand and make sense of their experiences.

#### 8.2.2. Lifeworld fractions

As presented above, the lifeworld includes seven fractions that assist in producing a phenomenological description of an experience. These fractions provide a framework that enables the researcher to focus while describing different scopes of the experience. They can be viewed as a basic structure for the explanation of the lifeworld. Each fraction imposes its own theme on the lifeworld without being detached from the other fractions.

Embodiment refers to the relatedness of feeling of the self and the body to a given situation; how we bodily live with others in the world. The embodiment fraction relates to the disruption of womens' bodies associated with pelvic organ prolapse and its impact on how the women relate to others specifically in the experiences they describe associated with intimacy and life within the family. This also has relevance to the fractions of selfhood, spatiality, and project. Selfhood indicates the sense of agency, feeling, and social identity. In terms of Saudi women with prolapse, this fraction shows how the world speaks of these womens' interests, concerns, choices, and behaviours. This is because the experience of prolapse is embedded in a world which already speaks of the womens' perspectives. Spatiality is concerned with the cultural context and social norms affecting a situation and how one reacts to the situation. Spatiality refers to womens' environmental context and their experience of living in that environment. In this study, the cultural background of Saudi Arabia is viewed as womens' environment. The way they interact with their environment and the qualities of that environment can have a positive or negative impact them. Project relates to how the activities that these women were doing were important to them and to what extent they are impacted by prolapse. Sociality refers to womens' relationship with others such as their husbands and other women in their families and how it was affected with their experience of prolapse. Discourse is concerned with describing the type of language the women used to address the situation. Temporality refers to the sense of time as it flows and unfolds in the present, determined by the past and future. Past events that are retained in memory that might affect women's present life, thinking about who she was or who she is now. Moodedness will examine the emotional tone of women with prolapse for example when they first noticed their prolapse and how it made them feel.

#### 8.3.Discussion of generated themes using the life-world theory

#### **8.3.1.** Conceptualisation of prolapse

Findings showed that women generally had no knowledge about prolapse prior to their experience. This did not stop them from attempting to make sense of what they were going through, that is linked to selfhood fraction of lifeworld. Respectively, women attributed different factors that caused them to have prolapse such as pregnancy and childbirth, housework, ageing, early marriage, and family history. These factors suggested that women thought of prolapse as an expected condition, which is explained by temporality. Women, therefore, adapted to prolapse and developed different self-managing techniques that helped them to ease the symptoms, linking to Ashworth's idea of project in an individual's lifeworld.

Women's conceptualisation and response to prolapse resonated with their cultural background, linking to the lifeworld fraction of spatiality. To begin with, lack of prior proficient knowledge about prolapse was reported by women in this study. Respectively, the experience of the initial symptoms was concerning and fearful to some. Lack of knowledge has also been reported by one cross-sectional study that was conducted in Emirates, this study demonstrated that Emirati women with symptomatic prolapse generally had no knowledge about the condition (Hammad et al., 2018). Emirates, Saudi Arabia, and all Arabian gulf countries share similar cultural background and religious beliefs hence this is of interest because it could highlight the role of culture in womens' knowledge about prolapse. Lack of knowledge about prolapse reported by women in my study and in the study of Hammad et al. (2018) could reveal some culturally critical issues that might be generalised broadly to Arab and Islamic societies. Considering the lifeworld theory by Husserl (1970), the cultural context shapes the situation one lives in and their response to it. Indeed, prolapse is a health condition that is reported to greatly impact women's quality of life (Jelovsek and Barber 2006; Şahin and Vural 2015). The impact of prolapse extends to women's sex life, making it a sexual health related problem. Fageeh (2008) described the culture in Saudi Arabia to be conservative as shaped by religion and social norms, hence, discussing sensitive matters like prolapse can be difficult for women given the social taboo surrounding sexual health related issues in Saudi Arabia. This is confirmed by my study findings and the findings of Alomair et al. (2021) who also demonstrated that sexual health education needs of Saudi women are unmet; however, the study of Alomair et al. (2021) did not include views of women with prolapse. Hence, this is the first study to highlight lack of knowledge about sexual health but among women with prolapse.

Lack of knowledge reported by women in my study was not surprising but understandable given the taboo surrounding issues related to sexual health in Saudi Arabia (Alomair et al. 2021). Indeed, findings suggest that Saudi women have never been formally educated about prolapse or other similar topics that are socially inappropriate to talk about. Hence, given the findings of the study of Hammad et al. (2018) and confirmed with my study findings, it can be understood that the cultural norms in Saudi Arabia and other middle eastern countries are critical in terms of women's understanding about pelvic organ prolapse. Previous studies have demonstrated that women in Arab societies are disadvantaged by these social norms in terms of their understanding of their sexual health (Alomair et al. 2021), and findings of my study further demonstrate that Saudi women are also disadvantaged because they had no previous knowledge or were not prepared for having prolapse at this stage.

It has been previously indicated that women in Islamic countries have limited access to formal sexual health knowledge or education compared to women in western societies (DeJung et al. 2005), which is critical to women's knowledge about prolapse. The culture and traditions in Islamic and middle eastern societies are informed by the misapplied Islamic religious laws. Historically, it is not forbidden in Islam to seek knowledge about sexual health related issues. Indeed, there a prophetic hadith that states that one should not be ashamed of gaining knowledge on sensitive matters particularly if it was relevant to understand the implication of that matter on religious practices. It is understood that the concept of forbidding to seek sexual health related knowledge has been falsely popularised by religious scholars and impacted the understanding of women in my study about prolapse. The study of Horanieh et al. (2020) has also touched up on this issue as it reported that views of stakeholders on implementing sexual health education to range from abstinence only to Haram reduction. Relating to lifeworld theory, the womens' environmental context or spatiality that included the cultural norms and religious beliefs in Saudi Arabia have governed their selfhood and resulted in their lack of knowledge about prolapse as they have limited access to such information.

Lack of knowledge about prolapse was also reported in the studies of Roets (2007) Pakbaz et al. (2011), Good et al. (2013), and Madimika et al. (2014). These studies were conducted in different cultural backgrounds where women are perceived to be more empowered than Saudi Arabia such as Sweden, South Africa, and the USA. There was however an agreement across these findings that women have limited knowledge about prolapse (Mandimika et al., 2014; Good et al., 2013; Roets 2007; Pakbaz et al., 2011). The findings of these studies might imply that the lack of knowledge regarding prolapse is not solely determined by culture, rather it could be attributed to the nature of the condition and the effects it has on their quality of life, which might make it sensitive to discuss in a variety of societies. It is perhaps explained by the implication of prolapse on a private area of womens' bodies, linking to the concept of embodiment.

In the study of Pakbaz et al (2011), women reported that their lack of knowledge was because they had limited access to educational resources about prolapse compared to urinary incontinence in Sweden. The impact of limitations in sex education resources have been reported to adversely affect women (Golchin et al. 2012; Alomair et al. 2021). Women in my study did not discuss any limitation in educational resources about prolapse; however, it is widely acknowledged that Saudi women generally do not have formal resources of knowledge for sexual health except in Islamic books in schools' curriculums (Saudi Arabia ministry of education 2019). Moreover, the provided information in school curriculums is limited to education about menstrual cycles and what women can and cannot do if they are menstruating. Women in my study asserted that they did not know what they were experiencing and their identified lack of knowledge about prolapse could potentially be explained by a lack of access to educational resources. It has been reported that Saudi women have limited knowledge about their sexual health (Alquaiz et al. 2012; Alharbi et al. 2018) and the findings of my study further confirm these claims but through the understanding of Saudi women who are around the age of menopause and are already experiencing the symptoms of prolapse. Additionally, it has been reported that women in Saudi Arabia have apparent misconceptions in terms of sexual health knowledge due the limitation of the right educational resources and their dependence on seeking health information from the internet (Alharbi 2018). Nevertheless, none of the women in my study indicated that they used the internet to look up their symptoms or increase their knowledge through this method, which is again linked to the concepts of spatiality and selfhood.

Lack of knowledge did not stop women from reflecting on their lives before they started experiencing the symptoms of prolapse and thinking about the possible factors that caused them to develop the condition. Through self-reflection processes, women identified five causes for prolapse namely: ageing, housework, family history, early marriage, and childbirth. The given causes suggest that prolapse was perceived as an uncontrollable condition or the natural course of the things as they did not have any formal prior education to inform their knowledge, explained by the temporality fraction of lifeworld. Despite the accuracy or inaccuracy of the identified causes, it was clear that all participants in this study were eager to make sense of their condition. Their lack of knowledge perhaps made them anxious to try and make sense as to why they ended up with a prolapse.

Based on the study findings, it is understood that the Saudi Arabian culture have informed womens' sense of embodiment. There was a consensus that frequent childbirth and housework have caused women to have prolapse. Women viewed these issues as a potential causing factor, but considering their lifeworld, these were choices that the society has already made for them, linked to spatiality. Women had specific roles in the family and the society that was determined by the Saudi culture. This affected the womens' selfhood and the sense of agency as the majority of women in this study were housewives and some have started the interview by identifying themselves as housewives. It was their personal choices that has been informed by the social norms in Saudi Arabia.

Childbirth has also been identified as a risk factor for prolapse by the women in the study of Gjerda et al. (2016) who agree that Ethiopian women, similar to Saudi women, have linked childbirth to prolapse. Essentially, the link between traumatic vaginal delivery (e.g. levator ani muscle tear) and prolapse has been well established in the literature (Dietz 2008). While childbirth can occasionally cause prolapse, this does not necessitate that prolapse is an inevitable consequence. Nevertheless, rather than childbirth, the frequency of childbirth was perceived to be problematic to some women in my study. The number of vaginal deliveries for women in the current study ranged between two to eight, yet there was a belief that the mode and frequency of delivery was to blame. By looking at the fertility rates in Saudi Arabia and Ethiopia in 2019, there appears to be a declining trend in the fertility rates in both countries over the past 30 years (World Bank 2021). In 1990 women in Saudi had on average seven to six children, whereas in Ethiopia, women had on average seven to eight children. Women in the current study and the study of Gjerda et al. (2016) were menopausal and they might be from the generations that preferred this high number of children under the force of society. High rates of fertility and tiredness in the post-natal period has made women in both studies consider childbirth as cause of prolapse. However, fertility rates did not seem to be under the control of women in my study, women did not discuss if they used any form of contraception neither were they asked about it during the interview, but evidence demonstrates that historically, large families have been favourable in the Saudi society (El-Haddad 2003). Again, the Saudi culture or spatiality have informed the gender ideologies and womens' roles in the family, their selfhood and agency over their bodies.

Selfhood is concerned with one's social identity (Husserl 1970). The women in this study identified themselves as housewives when asked to introduce themselves. Being housewives was a part of their sense of self, they are likely to have been involved in household duties since they were married, and some women like Lilly, Lujain, and Mai have chosen to remain in this role despite having a university degree or a job offer waiting to be accepted after they had given birth. Salwa said she gave up her education as soon as she got married. Aziza was the only woman in my study who did not identify herself as a housewife and mentioned that she has been working as a history teacher but had requested an early retirement, with no specific reason given. She further expressed her dislike of housework, and because of her different social identity, her experience of prolapse was different than other women in the study in terms of her reported symptoms and affected activities. Yet her response to her illness was shaped by her cultural and religious perspectives. Nevertheless, other women and their self-identification as housewives and the choices they made in terms of their roles might inform their priorities and life choices in terms of their roles as women in the society. Women chose to become housewives, instead of pursuing their careers and become more financially independent, which is a direct reflection of the social norms in Saudi Arabia (Velayati 2016).

Housework has also widely been regarded by my participants as a cause for prolapse. Women in the studies of Shrestha et al. (2014) and Gjerda et al. (2016)

also considered the heavy workload as one of the risk factors for prolapse. The workload reported in my study and in these two studies is relevant to women's roles in each society particularly household chores. The social norms impact the expectations from both genders in Saudi Arabia, Ethiopia, and Nepal despite the socioeconomic and cultural variations across the three countries. Heavy work has been reported in both studies as a causing factor for prolapse, however, frequency and perception of difficulty of housework varied between studies in terms of what women identified as heavy work. For example, Ethiopian women in the study of Gjerde et al. (2017) reported that they were expected to travel long distances to fetch water and participate in agricultural tasks whereas women in Saudi Arabia perceived housework to be heavy and led to developing prolapse. Some women indicated that the housework duties that were expected from them as housewives were tiring but they did not feel that it caused them to have prolapse rather they felt they were not able to maintain their duties because of their prolapse. Other women also discussed having a lot of expectations placed on them by family or society and both felt consumed due to intensive housework load, which is relevant to sociality and selfhood. Lilly said she would carry objects as heavy as a fridge around the house. Dina said she has been involved in intensive housework and that if she had a housekeeper, she would not tolerate the amount of work. Hence, both felt that housework was an important predisposing factor to prolapse. Women's perceptions of heavy work maybe a result of comparing the level of physical work they do to other women in their context. This further explains the difference in socioeconomic status and the variation in lifestyles among Saudi women and also between Saudi Arabia and Ethiopia.

Moreover, the studies of Gjerde et al. (2016) and Shrestha et al. (2014) reported that lack of rest following childbirth has been indicated as a causing factor for prolapse, women were expected to fulfil their expected roles as soon as they had their newborn. This has not been reported by women in my study. This is possible because postpartum rest is a critical ritual to women in some societies in Saudi Arabia (Abdulallah and Ali, 2007), indeed, in the first forty days or six weeks following childbirth, women often receive various forms of support from family and are only involved in caring for their newborn.

Identifying ageing as a causative factor demonstrates the women's views towards themselves that they were growing older. Aziza linked prolapse to muscle weakness due to ageing, whilst Lujain explained prolapse as an expected 'tissue sagging' that is also relevant to the aging process. Prolapse affected women's sense of embodiment and vice-versa. Some women thought they were growing older; thus, had prolapse, while others thought prolapse marked the first sign of ageing. The age of women in my study ranged from 49 to 62 years old yet they considered themselves to be ageing and growing older. Women included in this study were around the age of menopause, and cultural meaning of menopause in the Arab world means "the desperate age". The choice of name is relevant to women's inability to conceive after menopause, and it has been reported that women in Arabic cultures do feel desperate when they cannot reproduce anymore after their menstruation ceases, potentially marking the 'beginning' of the ageing process (Jassim and Al-Shboul 2008). It can be argued that, for the women in my study, menopause was an indication that they were ageing and shaped their views towards themselves and their understanding of prolapse, the change in their bodies have affected their selfhood.

Lilly was the only participant who explicitly demonstrated this negative outlook towards herself when she wondered why her period stopped and linked it to menopause. This was interesting because Lilly was 49 years old and was the youngest of my participants, yet she thought she was going through the "desperate age". The rest of the seven participants did not refer to menopause as "desperate age" and based on her narrative, it was understood that this has affected her quality of life. Lilly's understanding here can be explained by mix of lifeworld fractions that include temporality and embodiment "how her body changed over time", spatiality and discourse "the language she used to describe menopause that is relevant to how it is identified in her context", and selfhood "how she viewed herself after menopause".

However, some women in my study were likely impacted by this view despite not mentioning it overtly. For example, Lujain described herself to look younger than her actual age, but this did not stop her from believing that she was ageing given the changes that were occurring to her body. Nabeela was 59 years old and asserted repetitively that she was an old woman as her period stopped nine years ago and her health deteriorated afterwards. Nevertheless, perceiving themselves to be ageing or growing old at this age might be explained by Islamic religion beliefs. The prophet Muhammed has said "The lifespan for my Ummah is from sixty years to seventy years" This might impact the women's sense of embodiment, informed by spatiality, that they were approaching their sixties and developed prolapse; respectively, they understood that it was time for their health to deteriorate.

A systematic review by Al-Shaikh et al. (2016) identified that Saudi women are indeed reported to have multiple chronic health conditions. The age of women in the studies included in this review ranged between 18 to 89 years old. Moreover, one cross sectional study by Ibrahim et al. (2005) reported that older women in Saudi Arabia (aged 60 or more) are twice as likely to report symptoms of depression and anxiety in addition to experience different illnesses. Based on these two studies, and considering the views of women in my study, it can be understood that the health status of older women is generally poor in Saudi Arabia. This might have further shaped the realities of women in my study and their self-perception as ageing women 'their selfhood'.

It has been demonstrated that education provided to the women regarding the biological, psychological, and social changes related to ageing and self-care improves self-perception of ageing and group stereotypes, and significantly reduces any negative effects by improving emotional balance (Fernández-Ballesteros et al. 2013). There are no known similar regimens in Saudi Arabia that prepare women for any forthcoming stages of their lives, including menopause. Respectively, women in this study appeared to approach menopausal age with misconceptions about their health and perceptions that they are ageing and growing older and that it is time to experience different health conditions such as prolapse.

However, the association between ageing and prolapse is not yet fully established in the literature, with studies reporting contradictory findings. It is reported that the hormonal imbalance during menopause reduces pelvic muscle support (Dietz 2008), yet some argue that hormonal imbalances, particularly reduction in oestrogen levels, would lead to tissue stiffness making ageing less likely to cause prolapse (Goh 2003). Ageing is likely to cause prolapse in cases of pre-existing trauma to pelvic floor muscles through aggravating symptoms but identifying ageing to be the main causing factor for prolapse would incorrectly suggest that prolapse is normal with growing older just as women in my study did.

Ageing has also been reported as a causative factor for prolapse by women in the study of Shrestha et al. (2014), although the study did not provide any information about the ages of the participants. The study of Shrestha et al. (2014) was conducted in Nepal, and interestingly, life expectancy in Saudi Arabia and Nepal is similar. The world bank (2021) estimated that the total life expectancy in Nepal is around 71 years whereas in Saudi Arabia is around 75 years which might made women to think they are gradually approaching the end of their lives, and various forms of health deterioration such as prolapse are expected.

Lilly was the only participant who felt that marrying at an early age was one of the issues that caused her and her sisters to have prolapse. While early marriage or child marriage in previous literature has been linked to developing serious health conditions like cervical carcinoma and breast cancer (Alghamdi et al. 2015), there is no evidence supporting early marriage to be a risk factor for prolapse. Under the dimension of sociality, Lilly based this perception on her and her sisters realities, it was her sense making that was a result of being in the world sharing similar factors and health conditions with her sisters. Nabeela and Dina also felt family history was a causing factor as significant numbers of women in their families had prolapse, further implying the basis on which women broadly have conceptualised their condition on.

Factors such as childbirth, housework, and early marriage that were reported by participants demonstrate a lack of agency in terms of these choices and reflect that those women have a feeling of little or no control over these causes. Their experience in terms of having a large number of children, being consumed by housework, or getting married at a very young age were not their personal choices rather they were enforced by society. These concepts are further explained under spatiality.

In this study women attempted to make sense of their condition as something expected due to certain events in their lives. Lack of knowledge made them vulnerable and eager to find explanations for their condition. The women conceptualised prolapse as a normal condition that is a result of uncontrollable factors or social norms that shapes their social identity and their response towards it. The women felt no need to seek professional help but approached women within their families to understand their experience.

It is understood that the women's conceptualisation of prolapse in this study was mainly underpinned by cultural norms in Saudi Arabia and thereby personal subjective experiences. There have been various issues reported that were central to women shaping their experience of prolapse. To begin with, gender role norms have shaped these women's roles in society, instead of being members in the workforce and having the eligibility to be so, the majority of women chose to be a stay as housewives raising children and looking after the needs of their family. Respectively, men were financially responsible for the family (Velayati 2016). This appeared to feed into the already existing imbalance in family dynamics that was informed by religion conjoined with culture.

As the line between religion and culture is ambiguous in Arab and Islamic societies, the role of gender and subsequent inequality has been adopted by many Saudi men making them the dominant gender and making women submissive to their roles (Soekarba 2019). While these women's discourses were clearly suggestive of gender imbalance and inequalities, women did not explicitly discuss this as an issue. Women reported they had no choice in terms of pregnancy, marriage or in their roles in society. Mai said she had three unwanted pregnancies and felt this was out of her control, although the causes she provided during the interview suggested that it was under the will of her husband.

Dina and Lilly were tired of housework which was culturally expected from them as housewives. In fact, Dina said her husband did not believe she was sick until she fainted once and then he granted a release from housework. Lilly's involvement in housework and having an arranged marriage at early age, which she believed caused her prolapse, was beyond her control compared to western societies where women are more autonomous agents making their own choices and decisions in terms of childbirth with potentially fewer societal forces. This was different for women in my study whose lives were controlled by social norms, they were struggling yet did not admit it to themselves and tried to control their lives by accepting or offering things such as second wife or anal sex to try and make things better. The findings of this study are the first to highlight this issue among this group of women.

Based on the findings, it can be indicated that Saudi women generally have no, or very little, evidence-based knowledge about prolapse and when asked about the condition and what caused them to have prolapse, they frequently reported that the causes attributed to developing prolapse were as a result of their life course. This suggests that women felt that developing prolapse was inevitable or the natural course of things.

Women's responses to their condition were one of three, they either sought immediate help, delayed seeking healthcare support while knowing this is a condition that required intervention, and some of those who delayed seeking help adapted to their condition while practicing certain coping strategies. Lujain was the only participant who decided to seek healthcare support as soon as she experienced prolapse symptoms. Her response was prompted by her sisters' experiences of prolapse. She was told by her mother that according to her sisters' symptoms, her condition could get worse over time. Hence, her motive was more of a protective strategy as she was not currently bothered by the prolapse. Conversely, Lujain repeatedly asserted that her husband was bothered during intercourse, and through further analysing her narratives it appears that this was her trigger to seek immediate help, linked to sociality.

Zainab also demonstrated willingness to seek immediate help, but she did not know where to seek help until she was in the UK with her daughter, who it was acceptable to talk to about it, which can be linked to sociality. She had an active sex life, and her husband was not understanding of her condition. Seeking support was conditioned by the presence of her daughter. Zainab has three sons and a daughter. When she first experienced the symptoms, her daughter was abroad, and she waited to be with her daughter to seek professional help. Zainab's experience further asserted that experience of prolapse and responses in terms of healthcare seeking behaviour is mediated by culture. Discussing sexual health issues is regarded taboo in Arab and Islamic societies, and the response of Zainab suggests that sensitivity is increased when discussing these matters to males, even to male healthcare professionals.

Scott and Walter (2010) identified help seeking for a health condition as a process that involves the perception of symptoms followed by interpretation and appraisal of those symptoms, governing the decision, ability, and motivation to visit a health care professional to manage the symptoms. This suggests that the womens' response to prolapse is based on the interpretation and how they make sense of it. Nabeela, Salwa, Aziza, Mai, and Lilly delayed seeking healthcare support by choice and this could be relevant to their perception of prolapse as something nonconcerning (which has been explored above) in addition to the information they sought from family members or their past experiences with healthcare (further discussion of this is provided in themes below). Based on their interpretation of prolapse, these women had to develop coping strategies to adapt with the symptoms. Some women said they would take intermittent resting periods in order to ease the symptoms they were experiencing. Resting as a self-management method for prolapse symptoms has also been reported in the study of Gjerda et al. (2016). Additionally, women in the study of Gjerda et al. (2016) would rub oil on their prolapsed pelvic organ to moisturise it believing that it would help them with easing the pain.

One common health problem affecting women that is also caused by pelvic floor muscle dysfunction and is managed by physiotherapy methods is urinary incontinence. Al-Badr et al. (2012) reported that the prevalence of UI among Saudi women is 41%. Evidence shows that Saudi women with UI do not seek professional support (Al-Badr et al. 2012; Altaweel and Alharbi 2012; Abduldaiem et al. 2020). This is opposite to my findings as UI was one of the triggers for women with prolapse to seek support (see theme 4). In addition, the findings of my study are the first to report the response of women with prolapse to their illness. Salwa, Nabeela, and Mai have indicated seeking the support of traditional medicine practitioners or using traditional medicine remedies as a way of adapting to prolapse. In essence, seeking the support of traditional medicine or using their provided techniques to manage illnesses is a non-authorised yet common practice in Saudi Arabia. Indeed, one survey reported that a large proportion of Saudi

citizens are dependent on traditional medicine whether alone or associated with modern medicine (Bodeker and Ong 2005). Other studies reported that Saudi patients also used traditional medicine in the treatment of diseases like cancer, asthma, neurological and hepatic diseases (Jazieh et al. 2012; Al Moamary 2008; Mohammad et al. 2015). Findings of my study partially confirm the use of traditional medicine among Saudi women for managing prolapse instead of directly seeking the support of conventional healthcare, this is relevant to concept of spatiality.

The degree of Salwa, Nabeela, and Mai's compliance to any form of traditional medicine was in accordance with their beliefs. Salwa said she did not believe in traditional medicine yet had tried it as it was recommended to her by a friend, she discontinued the treatment following one session after seeing no improvement. Nabeela believed in traditional medicine effectiveness, and it was clearly a part of her heritage; thus, seeking support of a traditional medicine practitioner was the first thing she did as soon as she had the symptoms because of her mother's shared experience of prolapse that shaped her beliefs. To point out, the socioeconomic background of Nabeela was fairly different than the rest of the participant and she was the only one who asserted the significance of traditional medicine on various health conditions. For Mai, using traditional medicine has been a way temporarily coping with the symptoms; she felt that she had not been able to seek support due to frequent childbirths following the identification of the condition which is again relevant to her role within the family.

#### 8.3.2. Social support provided by family

This theme highlighted the position of family in womens' lives and the critical role family plays in their experience of living with pelvic organ prolapse. Findings showed that women disclosed their illness to at least one female family member women respectively received various forms of support. This theme is closely linked to the element of sociality in the lifeworld theory. Sociality is involved with the implication of others in a given experience (Ashworth 2007). Sociality in this study was discussed in the sense of familial relationship, particularly the womens' relationships with their children and other women in their families. The element of sociality has been critical to women in this study. Women had many active roles within the family in terms of caring for family members and looking after their needs. It is understood that family has been perceived to cause or contribute to prolapse due to women's caring responsibilities within the family, which aligns with women's roles towards family in Saudi Arabia (Al Alhareth et al. 2015). This is again relevant to the way these women interact with their environment and linked to the spatiality fraction of lifeworld.

Women in my study have shared the experience of a sensitive condition like prolapse with women in their families like mothers and sisters despite the taboo of discussing sexual related health topics in Saudi Arabia that has been addressed in previous literature (Alomair et al. 2021). This, to the best of my knowledge, was the first study to highlight that Saudi women have a strong familial bond that connected them with other women in their families, and this permitted them to share their experience of prolapse with them. The perception of prolapse as a natural part of aging or an inevitable consequence of what women have been through perhaps made women feel that prolapse is a common problem for women who have been through similar circumstances. Hence, women approached other women in their social context to share their experiences with them. Women in this study brought other women into their world to help them understand their experience and validate their conceptualisation of the condition. It was indeed an implication of how being with other women "or sociality" affected their experience of prolapse.

The lack of knowledge about prolapse and their sense making of the condition followed by approaching other women in the family suggests that women were in need of support. The lack of knowledge about pelvic organ prolapse has left most of the women in my study afraid and anxious despite their attempts to make sense of it affecting their mood under the idea of lifeworld. Fear and anxiety resulting from a lack of knowledge about prolapse experience were also reported in the studies of Roets (2007) and Ghetti et al. (2015). The women's understanding of prolapse in my study was limited; however, the explanation they provided of prolapse suggested that they felt the experience of prolapse at this stage was inevitable given the events they have been through, which again can be explained by womens' selfhood in terms of agency and temporality that this is how things are supposed be as they have been through different risk factors they believed have caused them to develop prolapse.

The women felt that they wanted a confirmation that their conceptualisation was correct. Maybe this understanding was developed after they spoke to other individuals. In fact, the findings of this study demonstrated that all eight women have disclosed their illness to at least one family member beside their husbands. Women spoke to other women in their family either mothers, sisters, or daughters. Despite the potential taboo of discussing intimate topics or topics related to sexual health that are enforced by religious beliefs and associated cultural norms, the women's tendency to speak to other women in their family about their condition and willingness to expose such facts about themselves was interesting. Firstly, it could be relevant to their fears and concerns and highlight that they were in need of comfort and support to reduce anxiety for a number of participants. Indeed, social support has been reported to reduce psychological distress in older adults with urinary incontinence in Canada (Corna and Cairney 2005). Secondly, it might be because of their understanding that prolapse is a common issue across women at this stage; indeed, Nabeela and Lilly had at least one female family member who had prolapse and they seemed to know this before they started their own experiences. The common experience of prolapse has created a shared understanding about the condition. Family had a degree of shared understanding. Understanding prolapse as a common problem has made it easier for women I spoke with to discuss prolapse and share their experience, reducing the potential culturally determined shame and stigma of discussing such a private issue to family members, it was a part of their being in that lifeworld.

Dina said that she also shared her experience with her wider family because as indicated earlier she had obligations towards her wider family. This is not surprising in the context of Saudi Arabia given the preference of joint family in the kingdom (Almalki and Ganong 2018). Indeed, Saudi Arabia has been described as a collective society where family bonds are valued, and this extends to wider family. Sharing the experience of prolapse with other women in the family is not unique to Saudi women, the study of Gjerda et al. (2016) also indicated that

Ethiopian women also spoke to women in their family like their mothers, sisters, and daughters about their problem. The Cultural Atlas (2021) reported that Ethiopian society also values long term commitment to both close family and the wider family. This could explain women's preferences to talk about prolapse in both countries. This was however contrary to the findings of Dunevan et al. (2014) where women reported being ashamed and embarrassed of speaking about their condition to anyone. Dunevan et al. (2014) study was carried out in the USA, that is reported not to be a collective society (Hoover and Nash 2016). In my study women broadly did not report being ashamed or stigmatised by the condition while sharing the experience of prolapse with female family members, however, Mai said she was only embarrassed to disclose information related to her sex life after prolapse to her sister. Other women in this study did not mention if they have shared intimate information to women in their families though. Nevertheless, the decision of Mai or any Saudi women of not sharing such intimate information with family members aligns with the cultural norms and can be explained by Ashworth's ideas of spatiality and selfhood.

As discussed earlier, prolapse was not disclosed to any male family member apart from their husbands. This again could be attributed to the potential taboo and sensitivity of discussing topics related to sexual health broadly in Islamic societies (Kingori et al. 2018). Zainab and Salwa both mentioned that their sons are in the medical and healthcare fields, they did not say that they personally spoke to their sons about their problem but said that their sons often attended their medical appointment with them. However, Salwa said that during her appointments, her physician would speak to her son about her condition, but he did not discuss things with her directly which left her further worried and trying to make sense of what they were talking about. The implication being linked moodedness in addition to sociality. The culture or "spatiality" for these women has determined that information these women could share or discuss with their sons despite they were in need for their support.

After speaking to their families about their illness, women received various forms of support. As discussed in the findings chapter some were given informational support as women in their families shared their past experiences of prolapse with them and advised them to seek professional help while discussing treatment methods. Other women reported that they were given emotional support as their family were understanding of their health condition and were no longer required to undertake housework related tasks or marital obligations. Some women received more tangible support as they were taken to hospitals to receive treatment and their appointments were often booked by their children because the appointments are booked through a mobile phone application and some women found it difficult. The social support provided to women in my study by family demonstrates in part the cohesion of families in Saudi Arabia that has been previously reported by Al-Khraif et al. (2020) which implies the family members in Saudi Arabia are committed to each other. From a wider perspective, Ell (1996) over 25 years ago indicated that families are primary sources of patient support and are commonly looked to first when support such as expressions of caring and love and practical assistance are needed. The experiences of my participants evidence that this is still the case.

#### 8.3.3. Prolapse and marital relationship

The findings of this study showed that the bodily changes as a result of prolapse caused the women to experience altered body image perceptions. Considering the lifeworld theory, the lived body is one of the elements of human experience and human consciousness, embodiment. (Ashworth 2016). Women in this study have used different words to describe the physical changes in their bodies after prolapse, some referred to it as a ball and one woman resembled it to a baby's head. Aziza has experienced childbirth twice and has been through the physical changes in the vaginal area during labour. Describing the prolapse as a baby's head is explained by her own experiences of childbirth particularly because her last delivery was complicated. Noting any changes in the area is a trigger for anxiety because of her memories of the bodily changes at that area as a traumatising event, which is relevant to the emotional tone or moodedness fraction of lifeworld.

One unforeseen finding in regard to the physical impact of prolapse was describing it as a "piece of meat" that has been provided by Nabeela. This could be justified by sociality, embodiment, and discourse. The findings showed that Nabeela's engagement with her mother during her mother's experience of prolapse has shaped her own experience. She has shared this relationship with her mother where she would look after her at times of illness, observe how she managed her health conditions primarily by traditional medicine approaches. Her social commitment with her mother was a significant part of her world and it respectively has shaped her sense of embodiment or the way she perceived her body after prolapse because she seen her mother's uterus following hysterectomy and also described as piece of meat that was black in colour. To her, she lost relationship with this part of her body.

The women's discourses about the physical impact of prolapse give an indication to the bodily changes that are associated with prolapse. In addition, the language they described is so powerful: ball, piece of meat, black in colour, and drop. These changes were shared across participants despite the subjectivity and personal nature of the implication of these changes. As discussed earlier, the alteration in body image was frequently reported as the first sign to these women that something was wrong. Indeed, women started talking about this particular symptom of prolapse during the interview, whilst scientifically, prolapse often reportedly starts as a heaviness or pelvic pressure and none of the women stated experiencing such symptoms (Schaffer et al. 2005).

Alteration in body image perception in the form of self-neglect and mental unwellness, "being wide", and vagina as a scary organ separate to the body have been individually reported by three women. The feeling of self-neglect and mental unwellness experienced by Lilly can be explained by the element of selfhood, she stated that she developed prolapse for reasons that she had no control over (see theme 1) and her response also implies that she had no control over prolapse or its symptoms; therefore, she experienced this mental state where she became resigned to the problem she had. In terms of "being wide" that Mai has reported, it could be explained by sociality, embodiment, and language. Mai had an active sex life and her husband's response (that will be discussed below) reflected that he was not pleased during sex. His presence in her experience and sharing intimate relationship with him has affected how she perceived her body. It might be that she was experiencing vaginal enlargement that affected her own pleasure, but her focus on this particular issue during the interview highlighted that her husband's response had impacted her perception, her selfhood. The element of embodiment could also explain Dina's perception of her vagina as a separate organ from her body. She had been damaged many times in this area by healthcare professionals during labour and for unspecified reasons. She has lost attachment with this part of her body and therefore was willing to have a hysterectomy despite being informed that there are other methods to manage the condition.

The association of prolapse and altered body image has been previously widely reported. The studies of Jelovsek et al. (2006), Zielinski et al. (2009), Lowder et al. (2011), Shrestha et al. (2014), Roose et al. (2014), and Hadizadeh-Talasaz et al. (2019) have all demonstrated that women with prolapse were more self-conscious about their bodies and the subsequent alteration of body image, and some have reported being less feminine. This issue of femininity was however not discussed by women in my study. This is again relevant to the concepts of embodiment and spatiality, and the meaning of femininity around the age of menopause in Arab societies. Identifying menopause as the 'desperate age' based on women's ability to reproduce arguably negatively affects womens' views towards themselves (Murphy et al. 2013).

This study was the first to report the implication of prolapse on the marital relationship of Saudi women. It was found that prolapse has affected women's marital relationship i.e., intimate relationship. Six out of eight women had active sex lives, three chose to stop having sex after developing prolapse and three maintained having active sex life. Considering selfhood fraction, one might assume that the three women who stopped having intercoirse had full control over this decision, but they did not, they decided to stop having sex whilst compromising in different ways such as offering husband to seek another wife or living with unspoken concerns about husband seeking other women.

Disturbed sexual function has also been reported by Jelovsek et al. (2006), Zielinski et al. (2009), Lowder et al. (2011), Shrestha et al. (2014), Roose et al. (2014), and Barber et al. (2002); and because of the reported dysfunction, women discontinued their sexual activity. The findings reported by Athanasio et al. (2012) and Ozengin et al. (2017) indicated that womens' sexual function was affected by prolapse, but the effect did not correlate with the stage of prolapse as women in later stages of prolapse had better sexual function than women at the earlier stages of prolapse. However, what was unique about the findings of my study is that the majority of women did not think their affected sexual function was personally problematic perhaps because women in my study broadly thought that sex was only important for men. This particular perception of women is governed by womens' spatiality in relation to taboo of women exposing their sexual need (Al-Zahrani 2011), and it has affected their selfhood in terms of implying what are womens' priorities in marriage as presented in findings. Some women also felt that their age had made sex less significant to them. This resonates with the concept of spatiality, embodiment, and selfhood in that women accepted these changes as a sign of ageing and perceived sex to be gender specific. This further demonstrates the views of participants towards themselves as women who are ageing in Saudi Arabia and surrounded by social norms that dictate the roles of men and women in society. Considering the idea of project, the womens' views also reflect that age affects womens' sexual abilities.

Women described the responses from their husbands in relation to the impact on their sex lives of prolapse and it further has shaped the womens' decisions of seeking help. The majority of women felt that their husbands were understanding of the condition, with Salwa, Lilly, and Dina reporting that they had stopped having sex since their symptoms started. Their husbands' responses in a male dominant society like Saudi Arabia was surprising but it also opposed the common view towards men and women relationships in Saudi being imbalanced as reported in eastern and western literature (Bunch 2021). Nevertheless, Salwa said her husband has erectile dysfunction and she felt sex was no longer important to him nor to her. Lilly felt her husband was 'weak' and he was understanding of her condition and often demonstrated patience with her. From a cultural perspective, Lilly's view of her husband represented typical gender ideologies about the role of men in being dominant in the society and that their compassion would be misunderstood in such situations that further defines gender role norms in Saudi Arabia. Dina also said her husband was understanding as he loved her and was concerned about her. She did not view his response as weakness, but she was understanding of the societal power given to him and she told him to seek another wife. The decision to stop to

have sex was seemingly not problematic for these three women, their selfhood and decisions was informed by their sociality.

Evidence suggests that the marital relationships are imbalanced in Arab and Islamic worlds making men more dominant and powerful (Soekarba 2019). Given the responses of most husbands as indicated by the study participants, this rule does not fully apply to all participants. Mai and Zainab said that they have been forced to maintain having active sex life and to solve this issue. Mai said her husband was distressed by her condition and that sexual pleasure was important for her husband and he used sex as a method to cope with depression. Zainab said her husband as a man has sexual needs that needs to be fulfilled despite her illness. Both were concerned that their husbands would seek another wife if they failed to maintain an active sex life. Both felt pressurised into maintaining an active sex life, but the type of pressure was different: Zainab was obligated to sleep with her husband; whereas Mai was told to fix the problem and please her husband which she explained was the reason for using traditional medicine. The urge to please their husbands due to fear that they will seek another wife is a result of societal pressure. Their husbands did not threaten them to remarry but Zainab and Mai as sexually active women knew that their husbands have this option as allowed by religion. Sociality as informed by spatiality can explain Mai and Zainab's responses to their husbands responses.

Hadizdah et al (2019) also reported viable responses of husbands to their wives' sexual dysfunction as result of prolapse ranging from indifference to supportive; some women indicated that their husbands threaten them to remarry. This study was conducted in Iran which is similarly a conservative country that applies similar religious rules to Saudi Arabia. Women in my study did not report being threatened by husbands to seek another wife, rather, few women were concerned that their husband would do so as they were religiously allowed to and suggested it themselves. The study of Shrestha et al. (2014) demonstrated that women were threatened by second marriages but also have been harassed by husbands. Gjerda et al. (2016) indicated women would avoid sleeping with their husbands, so they did not find out about their problem. Women in my study did not indicate such response and all have informed their husbands about their experience.

The cultural impact on their sex lives made the women I spoke with feel that sex was significant only for men and they were obligated to please their husband at any cost. Mai and Zainab were required to maintain active sex lives despite their illness, Mai was told to "fix this problem" and she used many harmful substances such as salt and pomegranate peel to tighten her vaginal area and be able to please her husband sexually. This is because it is reported that culturally men have the upper hand in marriage in terms of ending the relationship or being allowed to seek another wife if unhappy with the first one (Alturki 1986). Similarly, Lujain indicated many times that she was not bothered by her condition but relating her experience to sociality showed that she was eager to seek help as her husband told her he was bothered during intercourse despite asserting repetitively that it was not problematic for him. Lujain's reality was based on her sisters' experiences who both had prolapse, both were disadvantaged differently by the condition making Lujain think she was blessed for having a good husband and wanting to make him happy sexually, so she does not have to go through what her sisters have experienced. Regarding the rest of the participants, Salwa, Nabeela, Dina, and Lilly they did not think sex was a critical issue, possibly because of their culturally enforced conceptions about sex for women as something non-significant.

## 8.3.4. Healthcare seeking behaviour and limitations in healthcare

This theme presented the womens' healthcare seeking behaviour and the decision to seek help or not for the sake of managing their condition, it further reflected their unfulfilled needs from healthcare. Most of the women have delayed seeking healthcare support for prolapse, and it was evident that elements of their lifeworld have shaped their healthcare seeking behaviour particularly in terms of the factors that acted as triggers or barriers to seek help. These factors are discussed below to explore why these might be significant to them.

The factors impacting on my participants healthcare seeking behaviours may be surprising for researchers from westernised background but are understandable and acceptable for me as a Saudi woman with Arab and Islamic background. The first factor was not being bothered by the symptoms of prolapse which has been reported by two women: Salwa and Lujain. Several studies reported that prolapse significantly affects womens' QoL (Digesu et al. 2005; Jelovsek and Barber 2006; Zielinski et al. 2012). Moreover, it can be broadly assumed that prolapse affects women's' sense of embodiment due to the symptomatic representation of the condition in form of vaginal bulging or protrusion, the sense of heaviness and pain (Hove et al. 2009). Not being bothered by the symptoms of prolapse could be related to the degree of bodily changes after prolapse they were experiencing and project under lifeworld theory, particularly their ability to fulfil their roles. It implies that Salwa and Lujain were experiencing mild symptoms that may not be limiting their activities or affecting their QoL. However, prolapse symptoms were not bothering to Salwa as she was self-managing her symptoms through stopping any activity that triggered the symptoms such as exercise or intercourse. Salwa's response can also be linked to the selfhood fraction, these activities were not a priority to her given her lifeworld. Whereas for Lujain, bothersome was relevant to the active roles she had within family specifically in her marital life. This can be explained by linking her experience to four fractions of lifeworld: embodiment, selfhood, sociality, and project. The physical symptoms of prolapse were not personally problematic to Lujain rather it was bothering to her husband as it was interfering with intercourse or her marital relationship with her husband who was facing difficulty during intercourse.

Poor past experiences with healthcare, that can be linked to temporality, have also been addressed as a factor determining womens' current healthcare seeking behaviour in the current study. This is indeed of relevance to women, Ashworth (2016) commented on the effect of past experience on the present and said that our present experiences are bound to the sedimented history of past experiences which we interpret or unreflectively live. The experiences with healthcare the women narrated during the interviews suggested that many had lost confidence and trust in healthcare and therefore chose to protect themselves from similar incidents being repeated. The decision of women to delay seeking support based on past healthcare support would require these women to let go of their sense of agency over their bodies and handover their health to healthcare professionals who have previously damaged their health. It required compromise on behalf of women especially that their coping strategies were helpful, even briefly, in managing the symptoms.

Familial responsibilities appeared to have been either a trigger or barrier to seek healthcare support for women in this study. Womens' sociality "being with others and for others" have affected their healthcare seeking behaviour. Mai and Lujain delayed and sought support for factors related to their roles within their families. Mai for example was in need for help but was obligated to maintain her roles within family which was not under her control rather dictated by society. On the other hand, she was demanded by her husband to please him during intercourse as he was bothered by vaginal opening enlargement she was complaining of as a result of prolapse. As per selfhood and spatiality fractions, Mai attempted to control her life through self-managing strategies with the resources available to her to cope with prolapse in order to fulfil her roles as a housewife towards her children and her husband. She was juggling these two roles through controlling her symptoms and took control again by seeking healthcare support when her coping strategies were not working.

The presence of Lujain's husband in her experience, particularly in terms of having an active sex life, also affected her healthcare seeking behaviour. She chose to immediately seek support once she was informed that prolapse required intervention. What was unique to Lujain is that she asserted many times during the interview that she was willing to cope with prolapse without managing it through any method but the need to have an active sex life have shaped her healthcare seeking behaviour. Her healthcare seeking behaviour aligned with the social norms and gender ideologies in Saudi Arabia that can be viewed as a spatiality fraction. Given that Saudi men are allowed to seek another wife in case the first wife is not able to fulfil her roles and expectations (Alturki 1986), this affects womens' moodedness causing them to feel anxious and threatened even if the husband did not complain.

The experience of urinary symptoms has also been identified as a trigger to seek professional support, this further confirms the findings of Barber et al. (2002) where women perceive UI to be more problematic that prolapse. This perception can be explained by the elements of embodiment and sociality under life world theory. Salwa, Aziza, and Mai said that they lost bladder control and it caused them to use the restroom more frequently. This was embarrassing to Mai particularly to

been seen by others, but she coped with limiting her water intake; therefore, it was not what triggered her to seek help. Conversely, Salwa and Aziza said that this triggered them to seek healthcare support. It might be relevant to their sense of embodiment and the need to be clean as from a cultural/religious perspective, these women are Muslim and are required to pray five times a day and should be clean before praying. UI was interfering with their sense of being clean, they sought support not because prolapse was an issue but because UI was affecting their cleanness and they had religious obligations they needed to maintain. Nevertheless, this particular finding is contrary to previous literature that reported that Saudi women with UI do not seek professional support (Al-Badr et al. 2012; Abduldaiem et al. 2020)

The physician's gender was also one of the determinants of healthcare seeking behaviour. This aligns with the social norms in Saudi Arabia particularly because prolapse is linked to sexual health. A survey by Alyahya et al. (2019) reported that Saudi women preferred a female physician for psychosocial counselling and when visiting a gynaecologist, obstetrician, or urologist. Lilly said she disliked hospitals and she would delay going to hospital even when she was in labour. Lilly had always been seen by a male physician during her visits to hospitals, and she wished not to be seen by a male physician again for this particular problem. Seeking support of a male physician means that women would need to expose private body parts to him which may not be acceptable to women from conservative society and supportive of gender segregation in healthcare. This is related to the idea of spatiality and how her being in the world has affected her selfhood in terms of the decision she made about to be or not to be seen by a male physician.

The physician's marital status also appears to be critical when it comes to seeking support for a sensitive health problem as it controls the amount of intimate information women share about their experience. A number of participants asked about my marital status during the interview, particularly when they wished to disclose information about their sexual health. Knowing that I am a married woman with children was relieving to them and they felt that I would be more understanding of their condition. These feelings are relevant to their lifeworld; it is socially unacceptable in Saudi Arabia to talk to young and unmarried women about sexuality even for healthcare purposes (Alomair et al. 2021). This appeared to be limiting women from fully disclosing their concerns to physicians. Moreover, this made them feel that I shared the lifeworld with them and that we as married Saudi women with children have a shared understanding about what is appropriate to discuss and what is not.

One unique finding was that Aziza delayed seeking help for fear of being exposed. The religion of Islam emphasises the need for women to cover their bodies, not to be exposed and to wear modest clothes. Islam, however, is regarded as a religion of openness and moderation. It does not interfere with women's' need for seeking healthcare support. Aziza was a woman with strong religious beliefs, and it has controlled her selfhood, she prioritised her religious beliefs over her health. It has been presented in chapter (2) that religion and culture are parallel in Saudi Arabia, yet none of the other women reported a similar response to Aziza.

Aziza, Mai, Salwa, Nabeela, Lilly, and Zainab identified several limitations in the healthcare system when they attempted to seek help for their condition. Access to specialised doctors has been identified as difficult by some women and reportedly caused their symptoms to regress while waiting for appointment. This is perhaps explained by the limited number of specialised urogynecologists at the hospital were participants were recruited from in Saudi Arabia. Al-Zahrani (2011) also reported issues with service provision for sexual health: such as long waiting times and unsatisfactory level of care in Saudi Arabia. Moreover, the study of Al-Zahrani (2011) also highlighted the driving ban law for women in Saudi Arabia as a barrier for women to seek healthcare support, that resulted in women depending on their husbands for transport. This represented a major obstacle to accessing sexual health care or advice. Although the driving ban was lifted in 2017, few women in my study reported difficulty in transportation and dependence on sons to take them to hospital. In terms of the quality of care women in my study received, none have spoken about the quality of service provided.

The issue of miscommunication on behalf of healthcare professionals has been reported by some of the participants but it was evident in both parties - women did not share their full concerns with physicians and physicians at times did not discuss or explain the condition and treatment plans with women when they sought support. As a result, some women felt that their feelings of illness were being contracted or they were not given priority in terms of appointments, affecting their selfhood and moodedness.

# 8.4.Chapter summary

The lifeworld theory was considered to position my interpretation of the findings in a wider social and cultural picture, which might enhance the understanding of the experience of prolapse among Saudi women. The lifeworld fractions including embodiment, sociality, spatiality, selfhood, discourse, project, moodedness and temporality, were used to map the results in the existing literature. This chapter has created a theoretical interpretation of findings drawn from the results. The lifeworld theory provided an in-depth explanation of the experience of Saudi women with prolapse. It filled the gap within the literature and demonstrated the role of culture in shaping the lifeworld of women and their experience of a culturally sensitive condition as prolapse. Indeed, such understanding enabled me to highlight a contribution to knowledge, implications of research and suggestions for future recommendations, which will all be discussed in the conclusion chapter (chapter ten).

The next chapter explores the research quality and validity issues and my reflective experience as a researcher.

# 9. Chapter Nine: Validity and Quality Issues, Together with Researcher's Reflection on Research Journey

# 9.1.Introduction

This chapter seeks to consider the quality and validity of this study. It begins by discussing Yardley's (2000) principles for assessing validity and quality of qualitative research designs. The chapter will conclude with a reflection on the research process and the personal experience of undertaking this study.

# 9.2.Dimensions of quality in qualitative research

Smith et al. (2009) proposed that Yardley's guidelines should be considered and used to assess the validity the methods employed in any IPA study. IPA guided the research process in this study; therefore, the suggestion of Smith et al (2009) is taken in consideration here. To point out, Yardley principles are also useful in other forms of qualitative research.

As per Yardley's dimensions of quality in qualitative research, there are the four identified principles for assessing the worth of qualitative research (Yardley 2000):

#### Sensitivity to context

Theoretical; relevant literature; empirical data; socio-cultural setting; the participants' perspectives; ethical issues.

#### **Commitment and rigour**

In-depth engagement with topic; methodological competence/skill; thorough data collection; depth/breadth of analysis.

# Transparency and coherence

*Clarity and power of description/argument; transparent methods and data presentation; fit between theory and method; reflexivity.* 

# Impact and importance

Theoretical (enriching understanding); socio-cultural; practical (for community, policy makers and health workers).

The essential qualities are shown in bold with examples of the form each can take shown in italics.

For this thesis, Yardley's (2000) guidelines and principles have been chosen as they appear simple to follow and are both flexible and comprehensive. Moreover, IPA was primarily chosen as a methodological design for the current study and the analytical process was later changed to RTA (see chapter 6). However, IPA has guided the research process and methods and therefore using Yardley's (2000) guidelines for assessing the quality of this study seemed relevant. I will consider my thesis in relation to each of Yardley's principles, demonstrating the validity of the approach adopted and linking it together with the undertaken research process, ensuring the core concerns are recognisable and central in the thesis. There will, by necessity and congruent with qualitative approaches, be a flexible interpretation of these principles.

### 9.2.1. Sensitivity to context

Sensitivity to context was demonstrated by the wide range of literature review which focussed on the experience of women with prolapse (see chapter 3). Undertaking a scoping literature review has helped me in identifying the research aims, questions, methodologies, and methods. It also facilitated the discussion of findings that are supported by the relevant literature. Yardley (2000) stated that awareness of the relevant literature and previous related empirical work is crucial for all investigations despite the adopted methodology.

Another illustration of a sensitivity to context in this work is the awareness of the socio-cultural setting of the study (see chapter 2). My awareness of the socio-cultural context emerged because I shared this context with women. This research probed into the religious, social, educational, and cultural views that were demonstrably influencing women's beliefs about prolapse. The women's responses were a result of their relatedness to their world and the Saudi Arabian culture has greatly informed their experience of prolapse.

The social context of the relationship between me and the women who participated in the study also reflects sensitivity to context. I did not perceive the interviews as a discussion rather it was an act of meaningful communication where I engaged with what was being said. Moreover, I invoked the shared understandings which provided the framework for speech. For example, when discussing the impact of prolapse on womens' sex life, both the women and I were aware that this a culturally sensitive issue to discuss and I observed the womens' facial expressions as they were speaking about sex and understood when to probe and when not to.

Changing the plan of recruitment and the process of analysis from IPA to RTA can also be an indication of the research being sensitive to context. IPA necessitates linguistic analysis, but the data analysed in this study were translated by me from the Arabic language into English. The women in this study spoke about a hidden issue and their narratives in Arabic were unique to each one of them, however following translation the meanings may have been lost in translation. Adopting RTA for analysis demonstrates that a pragmatic sensitivity to context was achieved.

Several verbatim extracts from the responses of study participants were examined in order to be used as a support for a given theme or subtheme. This has ensured that the participants are given a voice, allowing readers to see how the interpretations were formulated (Smith et al. 2009). Sensitivity to context was similarly achieved through linking the themes to form subordinate and superordinate themes (see appendix I).

Frey (2018) has defined generalisability as the degree to which the results of a research study reflect what the results would mean in the real world. In other words, the results of a research are generalizable when the findings are true in most contexts with most people most of the time. In quantitative research designs, generalizability is optimized when samples are randomly chosen, the research environment and researcher behaviours are carefully controlled so as the outcome is not affected, and constructs are defined and measured in ways that validly and reliably represent the broad ways that variables operate. Quantitative research framework is often oriented towards horizontal generalization and wish to

conclude that there would be similar results with another sample drawn from the same population.

There is a different understanding of generalizability in the qualitative research framework and some qualitative researchers argue that generalizability is not the goal of social science research (Leung 2015). Nevertheless, there are some generally accepted generalizability criteria if a study aims to understand findings in a wider context. It has been stated that qualitative researchers are often more interested in vertical generalization, the extent to which research findings add to building or understanding theory. Being a qualitative research, this thesis has attempted to consider the vertical generalisations in the discussion chapters by attempting to link the particular experiences of women with prolapse to the abstract and the work of others (Johnson 1997)

The analysis of the study data has been manifestly sensitive to the data itself. The decision to employ Huessrl's life-world theory to explain the study findings was made after the completion of data analysis. Hence, following the analysis, my understanding of the experience of women with prolapse has been actively sought, minutely examined, and satisfactorily accounted for (Yardley 2000).

# 9.2.2. Commitment and rigour

Conducting an in-depth interview requires substantial personal commitment and investment for a researcher in order to understand participants' views (Smith et al. 2009). As this study was guided by IPA, I initially sought to develop my understanding and acquire the skills necessary to carry it out effectively because IPA was a complex approach to a novice researcher. I have attended online workshops that covered how to develop interview schedules, improving of interview skills through role playing, and the developing my analytical skills by practicing on examples. After changing to RTA, I undertook in-depth reading about the approach and watched Braun and Clarke's recorded sessions on RTA and how to effectively carry it out.

My commitment to this research was further demonstrated by the care I have shown to my participants during the interviews. The open-ended questions and the minimally structured approach attempted to show each of the women respect and inculcate the interviews by valuing their unique perspective. Their willingness to participate and to openly answer my questions supports my commitment, sensitivity and transparency.

The rigour of qualitative research methodologies is often debated. Unlike quantitative research where the rigour of the study is ensured in a more straight-forward manners for example through statistics and figures; Sandelowski (1986) stated that the rigour in qualitative research is a major concern that is a result of a lack of literature discussing it. Rigour has been linked to the validity and reliability of research. Qualitative researchers have different philosophical stances varying from realist to relativist, and each stance have its own definition of what rigour means. Research under interpretivist paradigms is often criticised for a lack of criterions on how the interpretation is judged.

As per Yardley's principles, rigour in this study was demonstrated by the completion of data collection and analysis. The sample used in this study has divulged the information needed for a comprehensive analysis, this was achieved through the recruitment of women who have prolapse and are around the age of menopause. The experience of prolapse was unique to each woman, hence, the analysis was undertaken on an idiographic level (see appendix G) and then moved to identifying shared meanings across womens' experiences (see chapter 7).

## 9.2.3. Transparency and coherence

Transparency is concerned with how clearly the stages of a research are described. As indicated in the previous chapters, a clear and detailed guide to the literature review, the selection criteria, and the search strategy were laid out in a grid table. The methodology and methods were comprehensively discussed, with the chapter providing a complete explanation of each step carried out in the study.

Reflexive skills can be considered as a part of the concept of transparency. Historically, Steier (1991) defined reflexivity as a turning back of one's experience upon oneself. It is aimed at controlling the preconceptions the researcher holds yet some biases the researcher holds might remain as they may be imbedded in their unconsciousness. Nevertheless, as per Colaizzi (1973), reflexivity is considered as an important part of the research process. This is because acknowledging personal

preconceptions, biases, and suppositions before dwelling on participants' stories and descriptions would help the researcher to self-reflect on whether his/ her interpretations are relevant to his/ her preconceptions or the participants. Indeed, Finlay (2009) suggests that adopting a similar recursive approach may help the researcher to look at participants' experiences in a fresh way.

In this study, transparency was also supported by the constant reading and rereading of the transcripts before during and after data analysis. It was also helpful for me throughout the research journey to re-listen to the interviews with the women and recall the interview process. I remained constantly immersed and engaged with their stories, they became very familiar to me, and their individual voices were consistently heard as well as supporting understanding of their shared experience. Moreover, the raw data interview transcripts available to be seen. The way that I moved from idiographic analysis to cross cutting themes made explicit through the use of mind maps (see appendix I). Looking at the raw data and then follow the presented mind map would show how I got from some of the statements to the theme to the discussion of the applicable theories.

Yardley (2000) described coherence as the "fit" between the research question, the adopted philosophical perspective, and the method of investigation and analysis undertaken to address study aims and objectives. The fit between the research question and aims and the research approaches has progressed together with my understanding of what I was hoping to achieve. I was hoping to achieve more than a description of the womens' lived experience with prolapse. This required a deeper understanding of the context and the ability to link aspects of their practice to more theoretical contexts such as the lifeworld. A coherent trail was demonstrated throughout the thesis chapters.

### 9.2.4. Impact and importance

According to Yardley's framework, the validity of qualitative research can be evaluated based on whether these concepts inform readers about an interesting and important issue and how well a study was undertaken determining the impact and importance of the study. The usefulness, and the ultimate value of a qualitative research can only be assessed in relation to the objectiveness of the analysis, the applications it was intended for, and the community for whom the findings were considered relevant. The current study demonstrated an understanding of the lived experiences of Saudi women with prolapse and it showed the influence of the lifeworld on personal and social issues. The interpretivist paradigm and my epistemological and ontological stances confirmed that individual meanings are constructed by the experience of an individual person and the meaning attached to their experience of a hidden issue is a result of their sense making as women living in a particular context surrounded by certain social norms and religious beliefs.

### 9.3.Reflection on research journey

#### 9.3.1. Methodological

### 9.3.1.1.Sampling and recruitment

Penrod et al. (2003) identified the population that is hidden from general society when participating in a research project as "hard-to-reach". During the design of this research, the population of Saudi women with prolapse was identified as "hardto-reach", and it was expected that I would face obstacles during recruitment. Participant recruitment in healthcare research can be challenging for various reasons such as the cost and the time traditional recruiting methods take to find the population of interest (Tiffany 2006). It has been estimated by Puffer et al. (2003) that 60% of clinical trials are cancelled or delayed due to a lack of participant enrolment. Moreover, researchers often find it difficult to recruit hard to reach populations such as patients with rare medical conditions or when doing research on sensitive topics (Rockliffe et al. 2018). A Cochrane review conducted by Mapstone et al. (2009) on methods of improving recruitment to research concluded that broadly it was not possible to determine the most effective method of recruitment. In terms of research aiming to study hard to reach populations, Penrod et al. (2003) noted that snowball sampling is often utilised to gain access to members of the population being studied through other members of their community. However, this method of sampling poses a risk to participants of losing their privacy because the method requires that they are able to speak to others with a shared experience. Therefore, it was determined that purposive sampling would be used to access participants, in addition, it aligns with IPA framework.

The study plan included three participant recruitment streams (see chapter 5). It was initially planned that women would only be accessed through two public streams: community recruitment via distributing flyers and Twitter. The first stream failed to recruit any participants despite the variety of the locations. This could highlight the sensitivity of the issue and that the target population is indeed hard to reach. In addition, the failure of recruitment through this method could also be explained by the fact that women might not have been motivated by the flyer to enrol in the study and possibly more effort was required by me such as approaching women in person to talk to them about the study aims and objectives. However, I was concerned about the subsequent ethical dilemmas of recruiting women in person as due to the sensitivity of the condition, it might cause emotional disturbance to women.

Social media emerged as a valuable method of recruitment because it offers a number of recruitment benefits such as increasing exposure through snowball sampling and accessing hard to reach populations (Martinez et al. 2014). A number of studies have demonstrated the effectiveness of social media in recruiting participants with hidden conditions (Martinez 2014; Ramo and Prochaska 2012).

Facebook has been widely used by academic researchers to recruit participants in the form of adverts, private messages and groups (Rife et al. 2016). Twitter has recently begun to receive attention as an alternative method for recruitment (Sibona and Walczak 2012). Twitter has been defined a source of "big data" due to the large volume of publicly available data. There are number of factors that made Twitter favourable as a method for recruiting research participants. Firstly, Twitter is intended to provide a space for widespread conversations and sharing ideas (O'Connor et al. 2014). Thus, unlike other social media platforms, it is estimated that less than 10% of Twitter users make their accounts private. From a research perspective, this offered less restricted access to potential participants. Twitter based recruitment allows the researchers to target specific users by "mentioning" them in a tweet, which further enhances the chances of being retweeted (O'Connor et al. 2014). This is done through selecting the region where the tweet is aimed to be viewed and then selecting the budget that the researcher wants to spend

to promote the tweet; these costs about \$0.50-\$2 per engagement. The promoted tweet is then viewed on the user's timelines or in the timeline of trending hashtags. Moreover, it has been estimated that Saudi Arabia has the highest percentage of internet users who are active on Twitter (Twitter 2019).

To ensure that the recruitment tweet was viewed by the population of interest and to further increase exposure, I followed two steps respectively: mentioning specific users and promoting the tweet using the Twitter ads service.

## *Reflection on failure of Twitter as a method for recruiting target population:*

As demonstrated, tweets were initially posted from my personal account that gained only three responses via followers who retweeted it. It has been proposed that the success of a recruitment tweet is contributed to by the timing of the tweet. Indeed, it is indicated that posting the tweet early in the morning or late in the evening can improve the rate at which Twitter users can engage with it (Sibona and Walczak 2012). In addition, posting between Monday to Wednesday was more successful in recruiting (Sibona and Walczak 2012). Considering the timing of the tweet is highly recommended as it is likely that the tweet will only be viewed by users if they are looking at the feed at the time of posting the tweet. Despite taking these recommendations in consideration, the response rates were low. Additionally, I have professional relationships with few of the physiotherapists and members of physiotherapy professional bodies that were mentioned. These users often retweet and post tweets for research project recruitment but none of them responded to my tweet. In addition, one of the physicians who responded and retweeted my post had mentioned the twitter account of the faculty that I originally worked at; however, the posts were not retweeted by them.

The lack of engagement with the posted tweets and mentions could be considered from multiple perspectives. Firstly, physiotherapy research in Saudi Arabia has been dominated by certain specialities such as orthopaedics and paediatrics. In terms of urogynaecology, research in this speciality in particular is limited in Saudi. Indeed, the number of studies conducted in Saudi Arabia about prolapse is sparse. The current study therefore is the first study to be conducted specifically on the topic of prolapse in Saudi by a researcher of a physiotherapy background. It could be that Twitter users who were mentioned did not think the research topic was of significant importance.

Secondly, qualitative research designs, although considered important, are not popular methodologies for research in Saudi Arabia. Women were invited to come and speak to me if they were experiencing the symptoms of prolapse. It is possible that due to a lack of awareness of the significance of qualitative research and interviews as a method of data collection the users mentioned were not motivated to retweet.

The third possible explanation is the sensitivity of the topic under investigation in the context of Saudi Arabia. The posted recruitment image contained words that might be considered inappropriate or taboo in the Arabic language, such as vaginal bulging and pain during intercourse; hence they preferred not to be associated with a retweet.

The response rates to the promoted recruitment advertisement on Twitter are an indication that Twitter probably was not suitable as method of recruitment for the target population for this study - women around the age of menopause and living with prolapse. For five continuous weeks, the promoted recruitment tweet was seen by a total of 69,670 people. This may have limited the exposure of the promoted tweet only to women who have access to Twitter and who met the selected viewing criteria, which was relatively small.

Nevertheless, the current study was a qualitative methodology requiring 8-10 participants. Obtaining the consent of 10 users out of 69,670 users who viewed the tweet should not be problematic but none of the users seemed to be willing to take part in the study. Nine women contacted me on Twitter through direct messaging, and 5 women contacted me on the phone number provided in the recruitment advertisement. The 14 women were confirmed to have the symptoms of prolapse but none of them was interested to be enrolled in a study, and the main reason they contacted me for was to seek a diagnosis and confirm that they are not suffering from something serious. I tried discussing the research project with them and outlined that I was not able to provide a diagnosis. All women were invited to participate in an interview, but all declined. The difference in the type of data

gathered during clinical trials, surveys and qualitative research could further result in participants being reluctant to take part in qualitative research. This could be one of the reasons that the women who approached me did not want to take part in the study. Given the sensitivity of the topic in the context, taking part in a qualitative study that requires them to do so voluntarily could potentially pose a threat of being exposed especially as there will be no outcome or personal benefit to them.

Although I updated my Twitter account details for the purpose of the recruitment, I was a stranger to the target population and gaining their trust to take part in culturally sensitive research may have been challenging. My biography on Twitter was publicly visible to anyone who accessed my page, although the details might seem of a value to target population, I am a researcher at a university in the UK that they may not be familiar with, and I was asking them to share personal sensitive details with me to help me with my research. Details regarding my position as a demonstrator at one of the well-known universities in Saudi were also added to my biography in addition to being a PhD researcher at Cardiff University, however, this did not seem to influence the women to trust me to take part in the study. Indeed, one woman preferred approaching me through text messaging before speaking to me on the phone to confirm my identity and intentions, further highlighting trust issues.

After two months of unsuccessful recruitment, I thought of using Twitter in a more creative way to get further insight on what is going on with women with POP in Saudi and why I have not been contacted in the rate I was anticipating. The step of polling data from twitter was undertaken following the low level of responses yielded through using different methods in Twitter to reach the target population. It was an attempt to explore and further possibly explain why Twitter failed to recruit women experiencing symptoms of prolapse in Saudi Arabia, particularly, in the western province. I have initiated a poll on Twitter and promoted it to be seen by the same population of interest. The tweet was viewed by 40,533 users, and only 993 users voted using the poll. Only 25% have sought professional support for managing the condition, nearly half of the respondents, 42% were hesitant and embarrassed to seek professional support, and 33% considered it normal and that it did not require treatment. The findings of this poll however do

not correlate with what my study participants said, the majority of women in my study perceived prolapse to be normal. Results of the poll justified the outcomes of the recruitment process. First, it is important to clarify why the poll options were limited to "yes" and there was not an option for "no" as an answer. The population of interest in this thesis are women living with prolapse and I wanted the answers to be focused on them. Adding "no" as an answer would give me percentage of prevalence of POP among target population; women around the age of menopause and living in the western province of Saudi Arabia. Although important, I was more oriented towards exploring the behaviours of women living with the condition in order to further justify why I yielded low response rates and no recruitment if participants.

Out of 40,533 users who viewed the poll, only 993 voted. This indicate that women who met the viewing selection criteria do use Twitter, and it is possible that those who have access to Twitter are not experiencing prolapse symptoms. The findings highlight important issues about the target population. 42% of women living with POP out of 993 are hesitant to seek professional support; hence, reflecting the sensitivity of the condition in the context of Saudi Arabia. 33% considered it normal highlighting the need for educating women about the condition and the available treatment options. These findings further imply challenges in accessing female participants through public streams. Moreover, due to the nature of the topic, it could be that most women prefer being hidden and avoid voluntarily taking part in studies or seeking support.

Participant recruitment through these public streams was not successful. However, it has been reported that in qualitative research, the process of recruitment has been described as "challenging and resource intensive" (Archibald and Munce 2015). There seems to be lack of attention in the textbooks to recruitment challenges faced by researchers and strategies to overcome them. The lack of transparency in reporting the recruitment process in detail may misrepresent the reality of conducting qualitative research which focuses on topics that are not socially acceptable to discuss.

The sensitivity of the topic under investigation may have exacerbated the challenge in recruitment. It has been stated that the recruitment process is frequently reported to be difficult when the topic investigated is deemed sensitive by participants and researcher (Awad et al. 2016). Healthcare researchers investigate a wide range of sensitive topics that in turn enhance understanding of these conditions. It often involves questioning participants about sensitive and private aspects of their lives, posing challenges for them and the researcher; thus, challenging the rigor of the study as it is influenced by real people experiencing emotions to sensitive and difficult events in their lives.

A systematic review by Gentles et al. (2015) identified three issues that might hinder successful participant recruitment in sensitive research: obtaining consent, working with gatekeepers, and accessing participants. In the first stage of recruitment, issues were encountered in accessing participants and obtaining consent subsequently. Accessing and obtaining participants approval is often more challenging when the topic under investigation is sensitive in nature, which further results in concerns regarding confidentiality and autonomy for the participants. In essence, sensitive topics have been reported to slow the recruitment process. This might be true in terms of POP, despite being a health-related topic, as the link between this condition and sexual behaviour and intimacy might result in women avoiding discussing it. The way women might perceive themselves following the condition has been highlighted in previous literature; however, no information is provided regarding the potential challenges to recruitment. Being a young Saudi woman myself who has experience of interacting with women of different age groups in Saudi, I see that Saudi women often consider reproductive health and sexuality taboo to discuss, unlike any other health condition. This could be posing difficulties in obtaining the consent of the population of interest. Moreover, it has been indicated in the literature that women often experience shame and disgust by the condition, which might lead them to sense of stigma when being approached to take part. In addition, offering them a chance to speak about their condition to a stranger for a research purpose may further make the process difficult.

Only 25% of women responded to the poll had sought professional support. Hence, considering the challenges I faced in recruiting women through public streams, it was deemed appropriate to add a third stream of recruitment that guaranteed access to the target population. In order to overcome issues with sampling and

recruitment, Padgett (2009) suggested identifying places that enables access to participants who have key insight on the phenomenon under investigation and recruit them within those settings. In terms of the current study, the decision was taken to approach participants in hospital settings and to continuing recruitment through the above indicated public streams, excluding the Twitter advertising service. Participants were finally recruited from one of the hospitals.

## 9.3.1.2. The interviews

As indicated above, the recruitment process and identifying the method that would guarantee access to population was difficult and this was evidenced by the lack of womens' engagement with recruitment streams 1 and 2. After successfully gaining access to women with prolapse, it was anticipated that women would be hesitant to speak or would refuse to discuss intimate issues regarding their experience of prolapse. However, all women invited agreed to participate and spoke openly about their experience including how prolapse has affected their sex lives. Women were comfortable speaking and none of them mentioned being disturbed or bothered by the questions they were being asked. The information provided in the interviews were deep enough to result in a depth of analysis. This made me reflect, following each interview, on what made these women openly talk to me about the experience of a culturally sensitive issue. What appeared to explain their behaviours is the shared cultural understanding we had particularly as a result of being Saudi women who have been through marriage and childbirth. When talking about their experiences, one woman said "you know we women" to explain why she had prolapse. Other women were asking about my marital relationship to speak further about how prolapse affected their sex lives. Knowing that I am married has made them comfortable to speak and that I understand the sensitivity of what they were speaking about, and that I as a married woman was able make sense of what they were saying things like "the world down there" to describe their private parts or why it was not important for Lujain's sister to seek help given that her husband no longer sexually approached her. Both IPA and RTA acknowledges the role of researcher in interpretating the study data, hence, the shared understanding I had with my study participants was an important part of the research journey.

### 9.3.1.3. The analytical approach

van Nes et al. (2010) described the relation between language and subjective experience to be a two-way process; language is used to express meaning, but the other way round, language also influences how meaning is constructed. Giving words to an experience is at times a complicated process because the meaning of experiences may not be completely accessible for subjects and difficult to express in some languages. Therefore, in order to capture the richness of an experience, people sometimes use narratives and metaphors language (Polkinghorne 2005). Lakoff and Johnson (1980) believed that these metaphors are language specific and may vary from culture to culture. Nevertheless, women in this study spoke about a hidden issue that was culturally sensitive. Different metaphors and idioms were frequently used to elaborate on a given topic. For example, the words "down there", "the world", and "the area" have been used by different participants when speaking about the vaginal area.

Moreover, the words women used in Arabic to describe their condition and discuss its implication were not common among all the participants. Hence, the weight of some significant Arabic words the women in this study provided were less powerful following translation to English and it felt that some deep meanings were lost in translation.

van Nes et al. (2010) argued that translation between languages involves some level of interpretation. Indeed, the communicated message "or data in this study" in the source language has to be interpreted by the translator and changed to the target language in such a way that the receiver of the message understands what was meant. Me and my study participants spoke the same language; therefore, no language differences were noted to be present in data collection, transcription and during the first analyses. This is possibly because the first coding phase in IPA and RTA stays closely to the data. The language differences however occurred when interpretations were being discussed with my supervisors who obviously were of different cultural background and spoke a different language. van Nes et al. (2010) believed that the translation of quotes poses specific challenges to the researcher as it may be difficult to translate concepts where specific culturally bound words were used by the participants to express their experiences. And this was often encountered when I was asked to explain some of the translated words that I have used in relation to women's words in Arabic.

The final meaning of the words was shared across the women but how each woman expressed those words was entirely subjective and personal because of the hidden nature of the condition. These subjective meanings were important to me for the purpose of linguistic analysis under the use of IPA. At this stage of data analysis, it became apparent that, using an IPA approach to data analysis was difficult and at times impossible due to the commitment of IPA to linguistic analysis (Smith 2012). The translation of study data disconnected me from the original text. In attempting to achieve an IPA analysis of the data, it seemed that IPA might not be the best method of analysis for such a sensitive topic within a conservative society because of the translation of the original text and the focus of IPA being on linguistic analysis, which is highly dependent on linguistic expression by the participants; difficult given the hidden nature of the topic and the cultural setting. IPA has been used as a methodological approach in other previous studies conducted in Saudi Arabia but the topic under investigation was not as culturally sensitive or under-researched as prolapse. Indeed, one study was conducted to elicit the lived experience of women with breast cancer in Saudi Arabia (Almegewly 2017). Breast cancer in essence is a widely researched topic in Saudi Arabia, and there are annual awareness campaigns about breast cancers where women are educated about the condition and are advised to attend special clinics for screening. Moreover, it is observed that women, particularly celebrities, with managed breast cancer are often invited to TV shows to speak about their experiences. This perhaps resulted in women's narratives about the experience of breast cancer in the study of Almegewly (2017) to be similar to and might have eased or enabled the process of linguistic analysis. But in terms of prolapse, the way women spoke about their experiences, the prolapse itself, and the sexual implications of the condition was extremely varied in Arabic. This could be attributed to the hidden nature of sexual related health topics in Saudi (Alomair et al. 2021). However, my attempts in translating their narratives into English potentially eliminated those differences. Respectively, the translated versions of the interviews may have lost those uniquely embodied experiences which is exactly what IPA aims to portray, and

when analysing the linguistic component, it felt as if I was analysing my own words rather than those of my participants.

### 9.3.2. Personal

Women's health physiotherapy is a subspeciality of physiotherapy and is involved in the conservative management of pelvic organ prolapse. Women's health physiotherapy in the UK is referred to as Pelvic, Obstetric and Gynaecological Physiotherapy. Regardless of name, women's health physiotherapy services provide care for women antenatally and postnatally in the presence of musculoskeletal pain. The scope of practice also includes pelvic health issues such as incontinence, pelvic pain and pelvic organ prolapse. It also includes issues that are specific to women such as osteoporosis, and rehabilitation following breast surgery. Women's health physiotherapy benefits women across the life span, from the young athlete to childbearing age, moving to the age of menopause and elderly women.

There is currently no evidence focusing on the practice of women's health physiotherapy in Saudi Arabia; therefore, the discussion here draws upon my personal perspective. I am a women's health physiotherapist from the western region of Saudi Arabia. I was awarded my bachelor's degree in Physiotherapy in 2011 from King Abdulaziz University in Jeddah. I worked clinically in a number of hospitals in Jeddah until I started my job as an academic at Umm-AlQura University in Makkah in Saudi Arabia. Throughout my clinical practice, I have rarely had the chance to manage a patient with pelvic organ prolapse nor did I manage most of the cases mentioned above relevant to women's health physiotherapy, particularly pelvic health. Patients were typically referred to me for physiotherapy if they had post mastectomy lymphoedema. I would also see women for low back pain and later identify through examination that their back pain is related to prolapse. Generally, women refused to be treated for prolapse because they did not believe that the two problems were related and wanted to focus on their back pain that is more bothering and activity limiting.

In terms of my teaching experience as an academic, I have taught undergraduate students about women's health issues, through practical sessions providing verbal

information and using visual aids and simulation manikins. However, I have not had the opportunity to demonstrate how to assess and treat women with prolapse due to lack of recognition of women's health physiotherapy at a number of hospitals in the western province of Saudi Arabia. This was also in issue when I was an undergraduate physiotherapy student. In addition, I undertook a course about women's health physiotherapy that was taught by a lecturer of a different speciality and there were no practical sessions provided as a part of the course. It can be argued that compared to other subspecialities of physiotherapy that already have issues in practice, women's health physiotherapy is given very limited consideration in many universities in Saudi Arabia as an important teaching priority, and at hospitals as a profession that is an integral part of the multidisciplinary team. In essence, despite the growth in evidence-based physiotherapy practice and the increased need for physiotherapy in different subspecialties, it is also reported that physiotherapy still faces some challenges in achieving recognition as a crucial service within the healthcare system in Saudi Arabia (Alshehri et al. 2018).

My clinical and teaching experiences were undertaken between 2012-2016. Since then, there have been several attempts by different organisations to increase awareness and recognition of all subspecialities of physiotherapy through campaigns and educational resources targeted at the Saudi community and the healthcare system. Yet these efforts have not sufficiently included women's health physiotherapy, which is highlighted by the limited number of women's health physiotherapists compared to other subspecialities and thought to be as a result of the culturally sensitive issues women's health physiotherapy is involved with.

There are currently seven women's health physiotherapists in the western region of Saudi Arabia. I have had informal discussions separately with two such physiotherapists working in different hospitals in order to gain insight on their practice, and there was consensus agreement that the physiotherapy services are not very well utilised for women's health conditions. However, they believe there to be a growing interest in antenatal and postnatal physiotherapy but only in the private sectors. My motivation for looking at the experience of women with prolapse was driven by the acknowledgment that these women are a hidden population that are potentially struggling in silence. Urinary incontinence is another major issue for women at various stages, and, sadly, there have been many attempts to normalise incontinence for women after childbirth through advertisements about over the counter incontinence pads and medications to control leaking. In terms of pelvic organ prolapse, experiencing the debilitating symptoms of the condition and not seeking professional help could be reflective of deeper issues that must be explored. In addition, being surrounded by women of different ages, I have heard different stories about older women having prolapse but discussing it as a natural phenomenon, and stories from younger women complaining of vaginal opening enlargement few years after childbirth. From a physiotherapy perspective, I was aware that this issue was relevant to pelvic muscle weakness, and it might cause the development of prolapse in the future. Yet none of them spoke to me in the sense of seeking medical advice and the majority did not understand the role of physiotherapy in women's health conditions. In addition, none have considered seeking professional support.

From the literature, and my own clinical experiences and observations, there are two reasons that may explain why women with POP are not seen in physiotherapy clinics in Saudi Arabia. Firstly, the organisation of the healthcare system in Saudi Arabia and the issue of non-referral to physiotherapy that was identified in evidence. The second possible reason could be the Saudi women themselves and their experience that needs to be explored as there might be something of value to HCPs to learn. Hence, in order to further conceptualise the problem, I contacted three family medicine physicians and two urogynecologists in Saudi Arabia. The three family medicine physicians claimed that they often identify that the patient has pelvic organ prolapse symptoms during routine check-ups, and they rarely see a patient coming to the primary healthcare centres complaining of symptoms of pelvic organ prolapse. The urogynecologists indicated that a small number of women seek healthcare professionals when they have third or fourth degree prolapse, and that is when corrective surgeries are considered the most appropriate and suitable intervention.

These factors were indicators that the experience of Saudi women living with pelvic organ prolapse need to be investigated. This information would help to establish possible ways to help these women to reach out for help and the optimisation of healthcare service delivery, particularly for physiotherapy.

This study is one of only a few qualitative studies that has been conducted around a sensitive topic in Saudi Arabia. Despite the sensitivity of topic under investigation and the cultural taboo around sexual health related topics in Saudi Arabia, women in this study have shared in some great depth their experience of prolapse and its implications including the implication on their sexual life. The willingness of these women to engage in the discussion and share intimate information reflect their need to be listened to. Telling these women that I was there to listen to their stories and assuring them that their potential secrets are safe has been relieving to them. They viewed this as an opportunity to share sensitive personal information in non-judgemental environment. Indeed, many women thanked me after the end of the interviews saying that they felt relieved sharing information they have never shared with anyone before. This demonstrates that undertaking a qualitative approach for this research project was the right decision.

But following each interview I was involved in deep self-assessment to think what happened during the interview and how it could have been improved. With each interview I felt that it was important to make women feel comfortable and welcomed before starting the interview, making sure that they feel they were in a safe place and their concerns are valued. I initiated the interviews often with small friendly discussion to break the ice offering them beverages and snacks. I was also giving women the time they needed to speak deeply about their experiences with little or no interruption. I have actively listened with what they were saying while responding when necessary. I believe this has resulted in the depth of the interviews and women's level of comfort while sharing personal information.

The experience of analysing interview data was hard firstly because of the novelty of the experience to me. Secondly, because it was being undertaken in the middle of the pandemic while the world was going through time of uncertainty. It was a difficult time, I had to return to Saudi Arabia and distance myself from the academic community. Thus, I ended up feeling isolated and anxious that I was the only one who was struggling. This was followed by the death of one of my supervisors, Doctor Philippa Coales and the postgraduate research director, Doctor Tina Gambling. Both were significant persons in my PhD journey.

Analysing the discourse of women while in Saudi Arabia surrounded by the cultural and religious norms the study participants were speaking about made it difficult for me to fully engage with what they were saying. I was accepting things for their face value while failing to capture the deep cultural meanings that were critical to my research. I also feel that this was because I was analysing texts of a personal subjective experience that were translated by me. This resulted in changing my analytical approach from IPA that relies on linguistic analysis to RTA. Changing to RTA has been smooth and flexible compared to the complexity of IPA.

Addressing the study aims and objectives through qualitative methodology has been exciting and challenging. The journey was full of obstacles that I have eventually overcome with hard work and my dedication to this research project. Understanding qualitative research, the choice between paradigms and qualitative approaches was not easy for novice qualitative researcher like myself. The process was lengthy, time consuming, and at times, anxiety inducing. But after continuous reading and the support of my supervisory team, it was getting clearer, yet the full understanding was only achieved at the final stages of writing up the thesis

# **10. Chapter Ten: Conclusion**

This concluding chapter will identify the key aspects emerging from the completion of the thesis. It begins by revisiting the rationale for conducting the study and summarising the key research findings in relation to the research aims and objectives. The implications for clinical practice will be considered in relation to the three levels of healthcare; "micro, meso, and macro", and will demonstrate the study contribution to professional knowledge. The limitations of the study and proposed opportunities for future research will also be considered.

# 10.1. The study

Pelvic organ prolapse is a commonly explored topic in international research, but in Arab and Islamic societies, including Saudi Arabia, published literature is scarce. Moreover, from a personal experience as a women's health physiotherapist in Saudi Arabia, women attending urogynaecology clinics complaining of pelvic organ prolapse is rare. Equally, women with pelvic organ prolapse are rarely referred to physiotherapy clinics. This suggests that there is a missing piece of the puzzle that needs to be considered. This study has therefore explored the lived experience of Saudi women around the age of menopause with pelvic organ prolapse.

The aims and objectives of this study have been addressed using a qualitative phenomenological research design, reflexive thematic analysis was used to analyse study data. The qualitative methodology used in this study has aided in understanding the experience of eight Saudi women around the age of menopause living with pelvic organ prolapse symptoms that have not been surgically managed. Each of the eight women's stories were analysed using reflexive thematic analysis and shared themes or meanings were identified following capturing their unique experience (see appendix G). The key elements of the findings were discussed in the discussion chapter (chapter 8) and situated within the existing evidence base. Using in-depth interviews enabled deeper insight into women's lifeworld, the lifeworld philosophical framework and its elements were considered to achieve an understanding of the living with pelvic organ prolapse including embodiment,

sociality, selfhood, project, spatiality, discourse, moodedness, and temporality perspectives (Ashworth 2003).

## **10.2.** Summary of the key findings

The study aims and objectives have been addressed by achieving an understanding that there were shared cultural meanings in the context of women's life following the experience of symptoms of prolapse. Lack of sufficient literature supporting my arguments in introductory chapters can be considered a limitation. However, the philosophical framework used here acknowledge my role as a researcher in producing findings. Me and my participants shared the lifeworld, my arguments may not be supported be evidence, but it has been so by my participants because of the shared understanding we have.

The influence of the social norms as informed by the culture in Saudi Arabia on shaping the experience of prolapse was the main finding of this study. The social norms which influenced womens' thinking in relation to their condition included factors such as the level of sexual health education they were provided with, gender role norms, commitment to family and family dynamics, women's social identities, and the taboo of discussing sexual health issues due to religious and cultural beliefs. The womens' lifeworld and being in that world impacted how they made sense of prolapse and how they responded to it. For example, women had no prior knowledge about prolapse and this appears to be underpinned by a lack of formal sexual health education in Saudi Arabia at any stages of their lives.

Prolapse was perceived to be a common or an expected condition affecting women at the age of menopause. This was an implication of the social norms in the world they live in, which dictated their roles and expectations as women from having a large number of children, being bond to housework, and the changes occurring to their bodies particularly with advancing age and following menopause. These social norms also shaped the women's' responses to their condition because most did not seem to think it was important to seek early professional help as long as the degree of discomfort was personal.

Family is a critical source of support when it comes to the experience of such illness in Saudi Arabia. Again, this was relevant to the structure of families in Saudi

Arabia where joint or large families are society's preferred family structure. Women approached other women in their family and disclosed their illness to them. The women they spoke to were either their mothers, sisters, or daughters. Various forms of support were received by women from women in the study, including informational support and being advised to seek professional help. Yet findings showed that women were not encouraged to seek healthcare support.

The physical symptoms of prolapse have altered the womens' body image perceptions. In addition, it affected their intimate lives. Sexual activity in essence was identified by some women as one of the critical factors when it comes to seeking healthcare support for prolapse. Women who were sexually active reported that they sought support of conventional medicine or healthcare at very early stages compared to sexually inactive women who preferred to wait until their symptoms worsened. Indeed, most women who were sexually active were not threatened by husbands, but this was the impact of the gender role norms that resulted in women developing concerns about their husbands seeking another wife because they were no longer able to fulfil their husbands' sexual needs. In terms of the women who were not sexually active and delayed seeking help, this suggested that for being a sexual health related issue, women did not think of prolapse as critical or a prioritised condition that should be managed.

The findings also reported the healthcare seeking behaviour of Saudi women with prolapse. Factors like not being bothered by symptoms, familial responsibilities, sexual activity, physician's gender, past poor experiences with healthcare, and religious beliefs have acted as barriers or triggers to seek healthcare support. Women also spoke about certain limitations in the current healthcare system that do not fully meet their needs as women experiencing a sensitive health condition surrounded by social norms.

The findings of this study contribute to fill the gap in the Saudi Arabian "and Arab/ Islamic" literature and knowledge of prolapse by offering insight into the experience. Much of womens' discussions may not be prevalent in the Western system, but it reflected the womens' being in the world. What is applied in Western contexts may not be necessary applicable to Eastern cultures, and this was demonstrated by the lifeworld theory that has been applied to the experience of these women and it has helped to explain what it is like to be a Saudi woman experiencing the symptoms of prolapse. Therefore, it is important to be sensitive to how culture shapes the experience of prolapse. The lifeworld theory is a westernised theory; nevertheless, it has aided in the understanding of the experience of Saudi women with prolapse when applied to the findings of the study. The suggests that adopting this theory may help in understanding the experience of prolapse in different non westernised societies.

## **10.3.** Implication of research

Nelson et al. (2008) considered that any healthcare system is comprised of three subsystems which includes the micro (individual patient or healthcare professional, service delivery), the meso (organisational) and the macro (public health or strategic). These systems do not exist in isolation but interact with one another, and therefore, things which impact one subsystem will impact the other and vice versa (WHO 2002). Hence considering the research focus in relation to these levels of healthcare will aid in providing some indication as to how far reaching any potential findings may be.

## **10.3.1.** The micro level

At the micro level, the experiences of women are essential to provide an insight into the lived experiences of those who are living with prolapse. The experiences of the women provided their personal perspectives about the condition, and it also can illustrate how they perceive the issue as a member of a wider society, and therefore, the findings can inform the other subsystems (the meso and the macro) of healthcare. The information gained from women have highlighted their experiences and can be used to inform healthcare at both meso and macro levels.

Lack of knowledge about prolapse, that was enforced by multiple contextual factors has resulted in making women delay seeking help and this could exacerbate the problem. Women expressed a need to maintain their roles as wives and mothers and yet felt that these roles exacerbated their symptoms and caused them to suffer. Women seemed to have little knowledge but wished to talk about their experiences with other women who might be able to offer advice.

Based on the findings it can be stated that there is a scope to educate women and raise their awareness about prolapse as a serious health condition posing great implications to womens' lives. Educating women about the available management methods for the condition "either conservative or surgical" will benefit women in terms of helping them in making informed decisions about their health when they notice the symptoms of prolapse instead of accepting it as something expected to happen to women with age or normal after multiple childbirth, housework, early marriage or related to family history. Sex education in essence has been reported to have a positive impact in terms of making informed decisions (Mueller et al. 2008). Implementing education at school or following childbirth may minimise the shame and embarrassment of discussing prolapse as a serious health condition affecting women, this would prepare women for what they might face in the forthcoming stages of their life. Indeed, Ward et al. (2014) concluded that implementing sex education at school age has aided in reducing shame and stigma around menstrual cycle across women. If women do not know about these issues for causes relevant to cultural sensitivity, they will not be able to talk about their health when affected by such conditions.

Women showed a willingness to share their concerns and disclose their illness to other women in their family. Women in their family appeared to respectively share their opinions and knowledge as an attempt to provide support. For women who are distant from family or may not have someone to share their illness with, involving women in support groups after menopause might help women to feel less isolated. But this might not work for those who have decided to hide their condition as a coping mechanism. It is important to understand that every woman is different and has unique set of beliefs and support system. Therefore, the concept of support should be adjusted according to womens' cultural perspectives.

Some women said that their children were involved in their care by making their appointments or taking them to hospitals. The cultural norms in Saudi Arabia dictates that children often care for and support their parents. Thus, support should also be provided to womens children and families by also educating them about the need for pelvic organ prolapse to be treated. Healthcare professionals can also provide the perspective of their position as an individual, as a member of a healthcare profession, and as a member of a broader society but their views have not been explored because the focus of this study was to explore the lived experience of prolapse from those who experienced it which aligned with my epistemological stance (see chapter 4).

Nevertheless, women have spoken about certain limitation in their experiences with healthcare which included lack of communication and feeling not being fully listened to. Thus, embracing holistic approaches that acknowledge the physical symptoms or clinical representation of the condition and also involve the psychosocial aspects of women is recommended when managing prolapse. This is because prolapse in the context of Saudi Arabia can be identified as a sensitive and hidden health condition. Women's concerns and practices in terms of prolapse might be missed if the condition is managed under the traditional biomedical model. Holistic approaches such as biopsychosocial model might assist healthcare professionals in addressing the women's needs of healthcare sufficiently.

#### 10.3.2. The meso level

The experiences of women with healthcare have briefly provided an insight into how a hospital delivers care for women with prolapse, thus, it can be informative to organisations that provide healthcare services about service delivery. If this meso level is informed by womens' needs from a healthcare provider, then the priorities of the organisation will be designed to reflect and fulfil those needs.

Meso level are organisations concerned with budget holding such as hospitals. Educating women and raising their awareness about prolapse will inform their healthcare seeking behaviour and prompt them to seek professional support as soon as they identify the symptoms. Managing prolapse at early stages through conservative methods and physiotherapy (individualised pelvic floor muscle training program) are proven the alleviate symptoms (Hagen et al. 2014b), and may help preventing women from undergoing surgical intervention. Essentially, physiotherapists worldwide are well prepared to assess patients, provide treatment, improve function, and evaluate improvement. Due to the nature of their profession, physiotherapists are often aware of patients' psychosocial aspects as they sometimes can hinder or help in improving the condition. In addition, educating patients and providing home treatment plans is a part of their role, and the conservative management of pelvic organ prolapse is partially dependent on self-management through pelvic exercise.

None of the women have reported to be referred to physiotherapy to manage prolapse although it is a condition that requires the involvement of different healthcare and medical specialities. Therefore, it is also suggested that the model of 'multidisciplinary teams' should be encouraged and adopted by healthcare professionals. Physiotherapy has been shown to adequately manage different urogynaecology conditions including prolapse and because of the current healthcare system in Saudi Arabia, access to physiotherapy is only allowed through a referral system. Hence, physicians must be educated about the critical role of physiotherapy in the management of prolapse and should be encouraged to refer patients to physiotherapy.

#### 10.3.3. The macro level

A wide range of limitations in the current healthcare system have been identified by women in this study. This included difficulty making appointments using the internet, long waiting lists or delayed access to healthcare, and receiving wrong diagnosis or treatment. These issues have disadvantaged women from receiving support when needed. This was not surprising given the limited number of physicians specialised in urogynaecology particularly in the western province in Saudi Arabia. Nevertheless, as a physiotherapist, I am aware that women's health physiotherapists are well prepared for the clinical assessment and management of pelvic organ prolapse and other pelvic health conditions affecting women. Further, to be seen by a physiotherapist, the current system in Saudi Arabia necessitates that the patients must be referred to physiotherapy by physicians, a step that could hinder patients from receiving support at the right time. Thus, it is recommended for the healthcare system in Saudi Arabia to enable physiotherapists to be the first point of contact with patients. This would help in reducing the occupational burden on physicians but will also help women in receiving support as early as possible. Acknowledging the role of physiotherapy in the postnatal period will also be fruitful to the healthcare system. The current postnatal check-up for women in Saudi Arabia includes visiting the obstetricians to listen to patients concerns following delivery, and it is often done without assessment of the pelvic floor or abdominal muscles. Including physiotherapy in the postnatal assessment plan might help in identifying any injuries in the muscles that may cause problems to women after a period of time.

# **10.4.** Strengths and limitations

The strengths and limitations identified below were a result of issues that were encountered during the study.

- Literature around pelvic organ prolapse or sexual health in Saudi Arabia and broadly in Arab countries is scarce. I encountered difficulty in identifying relevant literature that I could use to support my arguments and thereby justify the undertaking of this study.
- Obstacles arose throughout the study process beginning with my scholarship and issues with funders regarding the study design. It was unusual for my funders at first to see a physiotherapist undertaking a pure qualitative methodology but convincing them has made me more assertive about the choice of study and methodology.
- The participant recruitment for this study was challenging and lengthy. The initial plan was to recruit women from the general population who have not sought healthcare support. I felt this would help in revealing further deep cultural issues. But this was changed following failure to recruit participants.
- The use of semi-structured interviews gave the participants the opportunity to explore various issues and share intimate information with me. They demonstrated a willingness to talk despite the cultural sensitivity of the issues they mentioned.
- The study included the views of women who sought professional help for pelvic organ prolapse, therefore the findings are arguably not representative of the views

of Saudi women who decided not to seek professional help because of the potential variations in their life-world fractions.

- The findings may not be fully applied to women from societies that do not share the cultural or religious background with Saudi Arabia. Nevertheless, it may be applicable where prolapse is a covert health condition.
- Demographically, the data was collected from one geographical area in Saudi Arabia and, therefore, the findings' generalisability into other settings could not be assumed as the data was collected from one hospital, which provided services for the western region. Thus, it would be interesting to view other regions and to see if experiences were similar, or if some tribal and cultural differences might exist between regions.
- Conducting interviews in the hospital setting was practical for accessing the participants easily however the setting was very busy. I also felt that conducting interviews in the hospital was not practical for some women because I sensed that they wished to finish the interviews quickly and return home to be with their family in the afternoon, which is generally a busy time for housewives. Furthermore, conducting interviews in the hospital setting was not ideal for women as they were concerned because their husbands, sons or daughters were waiting outside.
- As a researcher, I found it challenging to "break the ice" with interviewees and to encourage them to speak openly about private issues, such as their sex lives. Social norms discourage expressing and sharing negative emotions with others, indeed, some women were hesitant to speak openly about sex and referred to it as "this thing" or the "marital relationship". Respectively, when some women spoke about their sexual lives during the interview, I felt there was a barrier from myself to probe deeper into their stories.
- My experience in conducting interviews for research purposes was limited prior to this study. I felt that the first few interviews did not achieve the depth required yet they provided rich data following the analysis. After each interview I took time to reflect on my skills and this helped to improve the depth of the subsequent interviews.

- Because the data was collected and transcribed in Arabic and then translated into English, my academic supervisors were not able to check the transcripts against the recordings. Translation problems arose, because some Arabic words do not have clear meanings in English and some words lost their meaning through the translation process. This has resulted in changing the method of analysis from IPA to RTA.
- As a young Saudi female, I might share some cultural values that could be reflected in my interpretations of the results. Hence, the findings of this study are a result of my shared understanding with women living with pelvic organ prolapse in Saudi Arabia.
- The culture and religion in Saudi Arabia were intensively discussed throughout the study chapters. Building arguments about the culture in Saudi Arabia and discussing the arguments was not an issue. But discussing religion was not easy because I am a Muslim woman myself and as I have been educated in a school where it was forbidden to question rules of Islam. I have found it really challenging to find the line between discussing and critiquing my own religious beliefs and doing so in a cautious manner. Saudi Arabia is an Islamic country, and this study is funded by a Saudi University, so it was important to me to ensure that my arguments and discussions are within the rules and regulations.
- One major obstacle that occurred during a critical stage of this study was the COVID-19 pandemic that changed the patterns of working. I sadly lost one of my PhD supervisors Dr. Philippa Coales, and our Director of Postgraduate Research, Dr. Tina Gambling. I had to fly back to Saudi Arabia following the start of the COVID pandemic and therefore distanced myself from the academic community I had in Cardiff. This affected my direct engagement with the school as I was only able to watch the recorded sessions on intranet due to time related differences.
- This study reflects the work of a multidisciplinary team, it was conducted by a physiotherapist and the supervisory team included members of physiotherapy, nursing, and midwifery backgrounds.

# 10.5. Knowledge contribution

- This is the first study in Saudi Arabia that seeks to understand the lived experience of pelvic organ prolapse from the perspective of Saudi women around the age of menopause.
- This study is the first to report the response of Saudi women to prolapse, they delay seeking professional support and some are willing to seek traditional medicine at first instead.
- This study reported the barriers and triggers for Saudi women with prolapse to access healthcare which could be informative to policy makers.
- Previous study exploring the experience of prolapse highlighted the role of culture in shaping the experience, the current study demonstrated that culture impacts how the condition is experienced.
- This study provides a methodological contribution to researchers from nonwestern background and willing to undertake an IPA study on a sensitive topic, issues with translation may arise.
- The study used reflexive thematic analysis as a method of analysis, but the analysis was conducted on idiographic and then shared level which added to the richness of the analysis and deeper understanding of the experience.
- It is reported in literature that IPA is more about depth whereas TA generally is about breadth, doing case by case RTA resulted in broad and deep interpretation of the data.
- The study found that culture, family dynamics, relationships, gender, social position and belief systems are very important elements that shape women's perceptions of health and illness.
- This study has given Saudi women an opportunity to share their stories and revisit their experiences with pelvic organ prolapse, and the role of culture in shaping women's experiences was revealed.

- The study enhanced the sense of wellbeing and relief for some of the women who participated, although conducting the interviews was associated with a certain level of distress.
- It has been demonstrated that the current healthcare system does not fully fulfil womens' informational needs or needs of care for prolapse. Thus, this research should inform developments of the healthcare system to be culturally responsive and act on the limitations identified by women in this study.
- This study is one of the few PhD theses that has been focused on the issue of pelvic organ prolapse, searching for the term "pelvic organ prolapse" on orca shows that only two studies about prolapse were published from Cardiff university.

# 10.6. Future work

This thesis has highlighted important issues for future research projects, some of which may be developed as part of my professional activities as a researcher and a lecturer in the school of applied medical sciences in Saudi Arabia. Future research should continue to explore the experience of pelvic organ prolapse in Saudi women. For example, a longitudinal study aiming to educate women about pelvic organ prolapse in the postpartum period and then evaluate the impact of the knowledge they gained if they developed the condition around the age of menopause. This would help in identifying how and when to offer help to women in accordance with the social norms.

Another interesting area of research would be assessing women's willingness to receive information about a health condition as culturally sensitive as pelvic organ prolapse in urban areas like Jeddah and Riyadh but also in the rural parts of the Kingdom where stricter rules might be applied. Understanding this will assist in establishing methods to raise their awareness in accordance with their given responses.

As physiotherapy plays a critical role in the management of prolapse, an exploratory study of physiotherapists working with women's' health conditions could be conducted to evaluate their competence in dealing with prolapse and to explore the cultural barriers they might face when managing such sensitive conditions. The aim should be to overcome those barriers and enhance optimum service delivery to women.

Based on the current healthcare system in Saudi Arabia, it can be understood that physicians are the primary decision makers in guiding patients' treatment plans. None of the participants in this study reported being offered a referral to physiotherapy, despite the need for physiotherapy treatment, therefore it is also important to explore the views of physicians towards physiotherapy as the profession can play a critical role in supporting women with prolapse. Such data might facilitate a step change in the healthcare system, enabling women's health physiotherapy to be offered as a first point of contact to women with prolapse.

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#### Appendices

#### Appendix A: Ethical approval from Cardiff university

School of Healthcare Sciences Head of School and Dean Professor David Whittaker

Ysgol Gwyddorau Gofal lechyd Pennaeth yr Ysgol a Deon Yr Athrawes David Whittaker

12 June 2019



Cardiff University Eastgate House 13<sup>th</sup> Floor 35 – 43 Newport Road Cardiff CF24 0AB

Tel Ffon: +44 (0)29 20 688559 Email E-bost <u>HCAREEthics@cardiff.ac.uk</u>

> Prifysgol Caerdydd 13<sup>ed</sup> Llawr Ty Eastgate 35 - 43 Heol Casnewydd Caerdydd CF24 0AB

Fahda Al Shiakh School of Healthcare Sciences Cardiff University

Dear Fahda

# The experience and healthcare seeking behaviour of Saudi women with pelvic organ prolapse: an interpretative phenomenological analysis in order to inform physiotherapy practice.

At its meeting of *11 June 2019*, the School's Research Ethics Committee considered your research proposal. The decision of the Committee is that your work should:

## Pass –and that you proceed with your Research after discussing the reviewers' comments with your supervisor

The Committee has asked that the lead reviewers' comments be passed onto you and your supervisor, please see below.

#### Data should be kept for 5 years, not 15

Please note that if there are any subsequent major amendments to the project made following this approval you will be required to submit a revised proposal form. You are advised to contact me if this situation arises. In addition, in line with the University requirements, the project will be monitored on an annual basis by the Committee and an annual monitoring form will be despatched to you in approximately 11 months' time. If the project is completed before this time you should contact me to obtain a form for completion.

Please do not hesitate to contact me if you have any questions.

Yours sincerely

Mrs Liz Harmer – Griebel Research Administration Manager

> Cardiff University is a registered charity, no. 1136855 Mae Prifysgol Caerdydd yn elusen gofrestredig, rhif 1136855

## Appendix B: Ethical approval from King Abdulaziz university

KINGDOM OF SAUDI ARABIA Ministry of Education KING ABDULAZIZ UNIVERSITY Faculty of Medicine Ref.:		الميلكة الورسية السعودية وذلاة النغي جامعة الملك محيد العزيز حلية الطب الدقيم:
Date: /28/4/2019 Encl.:		لرسم التاريخ / / ١٤هـ التاريخ / / ١٤هـ المرفقات:
Dear Dr A M Sydo Re: Fahda Alshaikh		
	onse, concerning Fahda Alsha research at King Abdulaziz Ur	
women who are patier	esitancy in ratifying Fahda Al nt in our hospital in accordanc to undertake her researches.	
-	lize her opportunity and to acc e, I would be very pleased to h Cardiff.	
Thank you very much Df. Samera Al Basri Associate Professor & Consu Chairperson, Obstetrics and C Assistant Hospital Director o King Abdulaziz University H Email: <u>salbasri@kau.edu.sa</u> Mobile no#: +966 505653412	lltant Gynecology Department f Strategic Planning Iospital	
من . ب: ۸۰۲۰۵ جـــــدة : ۲۱۵۸۹ P.O.Box: 80205 Jeddah: 21589	۵۱ مناکس : ۲٤۰۰۵۹۲ / ۲٤۰۰۵۱ Fax.: 6408451 / 6400592	אסיגניז / זאסי-זר : 🕿 ד : 6952446 / 6952063

Appendix C: Participants recruitment flyer through public streams

هل تعانين من "الوباء الصامت"؟ إذا كان عمرك يتراوح ما بين ٢٥-٤٥ و تعانين من هذه الأعراض، فأنت مدعوة للمشاركة في بحث استطلاعي عن معاناتك. الشعور باحتقان أو ضبغط في منطقة أسفل الحوض. للمزيد من المعلومات يرجى آلام أسفل الظهر و الساقين. التواصل على الرقم: .00.9ATVEE صعوبة في التبول أو تبول لا ارادي. آلام اثناء الجماع وقلة الرغبة الجنسية. CARDIFF

#### **Appendix D: Interview Guide**

Part 1: tell me about your experience with pelvic organ prolapse

I would like to know what is it like for you to experience the symptoms of pelvic organ prolapse and how it might be impacting you.

- 1. What is it like to have these symptoms?
  - How much bothered are you by the symptoms?
  - How does it make you feel? Does it make you feel different?
  - How is it affecting your daily activities?
- 2. Lets talk about your social status and relationships:
  - Has anything changed since you started experiencing the symptoms?
  - Have the symptoms affected your social position?
  - Would that be OK if you tell me your current job?
  - Can you tell me if the symptoms have an impact on the roles expected from you as a "according to current job"?
  - Have you spoken to anybody about it? have you sought the support of your family and friends? Can you elaborate?
- 3. How about your relationship with spouse?
  - Are you currently sexually active?
  - Are the symptoms affecting your sexual activity?
  - How does it affect your sexuality and self-image?
  - How is it affecting your overall relationship with your husband?
  - What does he say about it? is he also bothered?
  - How is it affecting your intimacy with spouse?
- 4. Lets talk about managing those symptoms?
  - How are you managing the condition?
  - Is there any coping strategies you developed to ease out the symptoms?

Part 2: now I need to have more details on your thoughts and perception about the condition

- 1. What do you think has caused the condition in the first place?
- 2. Would you consider it a problem?

Part 3: how about you engaging with healthcare professionals?

- Have you thought of seeking professional support for managing the condition?
- Why you have not sought support yet?
- Do you think there is anything healthcare professionals can do to support you?

**Finally,** If we go back to the time when first started experiencing the symptoms, what could have been done to avoid the impact pelvic organ prolapse has left of your daily activities, social relationships, and your relationship with spouse?

• Is there anything else you would like to share with me so that I can really understand how this has been for you (and of course your family)?

• What would be your message for women experiencing the symptoms you are experiencing?

#### **Appendix E: Consent form and Participant information sheet**

Title of the Study: The experience of Saudi women with pelvic organ prolapse

Please read each section carefully before you initial each box.

I confirm that I have read and understand the Participant Information Sheet, for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and it will not affect the care I receive from the hospital.	
I agree to be interviewed by the researcher and the use of audio- recording, and understand that verbatim quotations from my interview may be used anonymously in the report produced from this study and in papers produced for publication and for conference presentation, but I can withdraw the use of any part of the material at any time before the report is published.	
I understand that if, during the interview, information is disclosed that may put me or others at risk, the appropriate health care team will be informed.	
I understand that data collected during the study may be looked at by Research Governance staff working in Cardiff University for the purpose of monitoring and auditing the conduct of the research. I give permission for this.	
I understand that data collected will not be transferred to any other organisation.	
I agree to take part in the above study.	

#### **Declaration by participant:**

I hereby consent to take part in this study.

### Participant's

name:.....Date:....

#### **Declaration by the researcher:**

- I have given a verbal explanation of the research project to the participant and have answered the participant's questions about it.
- I believe that the participant understands the study and has given informed consent to participate.

**Researcher's** 

name:.....Date:....

**عنوان البحث:** تجربة السيدات السعوديات مع هبوط أعضاء قاع الحوض و مدى تفاعلهن من الرعاية الصحية المقدمة لهن.

أؤكد أنني قد قرأت وفهمت ورقة معلومات المشاركين للدراسة المذكورة أعلاه. لقد أتيحت لي الفرصة للنظر في المعلومات، وطرح الأسئلة وقد أجبت على نحو مرض.
أدرك أن مشاركتي طوعية وأنني حرة في الانسحاب في أي وقت دون ذكر أي أسباب أو مبررات
أوافق على إجراء مقابلة مع الباحث واستخدام التسجيل الصوتي، وأدرك أن الاقتباسات الحرفية من مقابلتي قد تُستخدم بشكل مجهول في التقرير المنتج من هذه الدراسة وفي الأوراق التي تُنشر للنشر وللعرض التقديمي للمؤتمر، لكن يمكنني رفض استخدام أي جزء من المادة في أي وقت قبل نشر التقرير.
أدرك أنه إذا تم الكشف عن معلومات قد تعرضني أو تعرض الآخرين للخطر أثناء المقابلة، فسيتم إبلاغ فريق الرعاية الصحية المناسب.
أتفهم أن البيانات التي تم جمعها أثناء الدراسة قد يتم فحصها من قِبل موظفي حوكمة الأبحاث العاملين في جامعة كارديف بغرض مراقبة ومراجعة إجراء البحث. أعطي الإذن بهذا.
أدرك أن البيانات التي يتم جمعها لن يتم نقلها إلى أي مؤسسة أخرى.
أوافق على المشاركة في الدراسة المذكورة أعلاه.

#### تصريح المشارك:

أوافق بموجبه على المشاركة في هذه الدراسة.

اسم المشترك:

تاريخ التوقيع:

تصريح من الباحث:

•لقد قدمت شرحًا شفهيًا للمشروع البحثي للمشارك ، وأجبت على أسئلة المشارك حوله.

•أعتقد أن المشارك يفهم الدر اسة وقد أعطى موافقة مستنيرة على المشاركة.

اسم الباحث:

تاريخ التوقيع:

#### **Appendix F: Participant information sheet**

Study title: The experience of Saudi women with pelvic organ prolapse

#### Dear participant,

My name is Fahda Alshiakh, I am a PhD student at School of Healthcare Sciences at Cardiff University in the UK. I would like to invite you to take a part in this study. Before you decide whether you want to take a part or not, it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it either with other members of health care or family if you wish. Please contact me if anything is unclear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

#### **Purpose of the study:**

Pelvic organ prolapse is defined as the descent of pelvic organs below the anatomical position. It affects nearly half of women after pregnancy and labour, but symptoms start aggravating around the age of menopause. pelvic organ prolapse symptoms include pulling down feeling, bladder and bowel symptoms, and pain during intercourse or impaired sensation. This study aims to understand how the daily lives of Saudi women experiencing these symptoms are affected. Moreover, it aims explore how they engage with the healthcare services available for managing the condition. for this purpose, this study will explore the experience of married, Saudi women with pelvic organ prolapse at the age of menopause who have not sought healthcare support. This will be done through interviewing each women eligible for the study and the interview will take place either at King Fahad's General Library or King Abdelaziz university hospital in Jeddah and will last about 60-90 minutes.

#### Why I received the leaflet?

You have been invited to take part in this study because you are around the age of menopause and experiencing the symptoms of pelvic organ prolapse.

#### What will happened if I decide to take part?

If you choose to participate, you will be asked to fill in a consent form. Following that you will be contacted to choose your preferred time and day to be interviewed.

Please bear in mind, if you are suffering from any mental or physical disability, have any visual or speech impairment, you will not be eligible to be included in this study.

#### What next?

The interview will be located a private room in King Abdulaziz university hospital in Jeddah and will last up to 90 minutes and will be audio recorded. No one will have access to these records except me "the researcher" and my supervisors in Cardiff university. Please note that you will be asked to be interviewed alone.

During the interview you will be asked about pelvic organ prolapse and how it has affected your daily life, you will also be asked for information on sensitive relevant topics, for instance if pelvic organ prolapse has affected your intimate life with your partner.

#### What are the risks and benefits of participating in this study?

The information I get from this study may benefit others in the future. You will be helping me to understand the meaning of living with pelvic organ prolapse, as well as your experience with the disease. Furthermore, your participation could open a window for other women who shared the same experience and wished to improve their current situation and the cultural taboo about pelvic organ prolapse. Sharing your experience with me might help health care professionals tailor support and care according to your needs.

I do not expect there to be any disadvantages or risks associated with you taking part in this study. However, talking about your experience with illness could be a sensitive topic for you to expose. If at any stage you feel distress talking about your experience, I will evaluate the situation and remain with you until you reach a stable emotional state by demonstrating care and empathy and giving you time to express your feelings. You will be offered to either change the question to manage the interview pathway or terminate the interview without giving any reasons.

#### Will my taking part be kept confidential?

Yes, I will follow ethical and legal practice guidance of Cardiff University and all the information about you will be handled in confidence. You will not be identified by name and all procedures of handling storage and destruction of data will be kept confidential. I will collect data from the interview which I will do by taping the interviews and the information will be stored on my computer within the university with a password. The recordings will be locked in a secure cabinet with control access until transcribed and verified and then destroyed. After 5 years of keeping the data, Cardiff University will archive and then destroy the information.

Your participation in this study is completely voluntary and any information you share in connection with this study will be kept completely confidential. Details such as your name, location and contact number will be kept confidential throughout the study, publication and presentation by giving you a different name or number.

#### What if something goes wrong?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions (please check my contact details below).

If you remain unhappy and wish to complain formally, you can do this by contacting the School of Healthcare Sciences Director of Research Governance (Dr Kate Button <u>buttonk@cardiff.ac.uk</u> 02920687734).

In the event that something does go wrong, and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against Cardiff University, but you may have to pay your legal costs.

#### What will happen if I don't want to carry on with the study?

Your participation in this study is entirely up to you. If you wish to withdraw from the study, you are free to do so any time during the study, without giving a reason and it will not affect the care you receive from the hospital.

#### Who is funding the study?

The study is funded by Umm Alqurra university in Makkah.

#### Who has reviewed that study?

The study has been reviewed and approved by the Research Ethics Committees at Cardiff to protect your safety, rights, wellbeing and dignity.

If you have any further queries concerning the study, please feel free to contact me:

Fahda Alshiakh

Telephone:

E-mail address: AlshiakhF@cardiff.ac.uk

Thank you

#### معلومات للمشاركة في البحث

عنوان الدراسة:

تجربة السيدات السعوديات مع هبوط أعضاء قاع الحوض ومدى تفاعلهن من الرعاية الصحية المقدمة لهن.

المقدمة:

تسعى هذه الدراسة إلى استكشاف وفهم تجربة تعايش السيدات السعوديات مع هبوط او ارتخاء أعضاء الحوض والنظر في مدى تأثير ثقافة المملكة العربية السعودية على تجربتهن. أهداف البحث هي:

- دراسة تأثير هبوط أعضاء الحوض على النساء السعوديات وأنشطتهن المعيشية اليومية.
- استكشاف آثار هبوط أعضاء الحوض على العلاقة الحميمة للمرأة وعلاقتها مع الزوج.
  - تحديد ما إذا كانت هناك أي جوانب من حياة المر أة تتأثر بالحالة
  - البحث في كيفية إدارة النساء للحالة ، وإذا ما وضعن أي استر اتيجية للتكيف.
  - اكتشف وجهات نظر وتصورات النساء فيما يتعلق بما تسبب في هذه الحالة.
  - استكشاف تأثير الثقافة السعودية على تجربة السيدات مع هبوط أعضاء الحوض .

عزيزتي المشاركة ،

اسمي فهدة الشيخ ، أنا طالبة دكتوراه في كلية العلوم الصحية بجامعة كارديف بالمملكة المتحدة. أود أن أدعوك للمشاركة في هذه الدراسة. قبل أن تقرري ما إذا كنت ترغبين في المشاركة أم لا من المهم أن تفهمين سبب إجراء البحث وما ستشمل مشاركتك. يرجى قضاء بعض الوقت لقراءة المعلومات التالية بعناية ومناقشتها مع الأسرة إذا كنت ترغبين في ذلك. يرجى الاتصال بي إذا كان أي شيء غير واضح أو إذا كنت ترغبين في مزيد من المعلومات.

شكرا لقراءتك هذا.

#### ما هو البحث ولماذا يتم إجراء هذه الدراسة؟

هبوط أعضاء الحوض يصيب ما يقارب نصف السيدات بعد الحمل والولادة. يمكن أن يكون مصحوبًا بأعراض مثل الإحساس بضغط في منطقة الحوض ، ألام أثناء الجماع ، وصعوبة في التبول أو سلس بولي. و يمكن أن يصيب السيدات بدون وجود أي أعراض. النساء اللائي تعرضن لهبوط في أعضاء الحوض في سن بعد الحمل و الولادة " سواءا بأعراض أو بدون أعراض" من المتوقع أن يصبن بالهبوط في سن انقطاع الطمث. وذلك لأن الانخفاض في إنتاج هرمون الاستروجين يؤثر سلبا على دعم عضلات قاع الحوض ويستفر أعراض الموض

أعراض هبوط أعضاء الحوض تؤثر بشكل كبير على حياة السيدات. وقد أظهرت الدراسات أن هبوط أعضاء الحوض أثرت على صورة المرأة الذاتية وتصور الجسم بالإضافة إلى تأثر العلاقات الاجتماعية والجنسية. في الواقع ، كان مدى تأثير التدهور على حياة النساء يعتمد إلى حد كبير على الخلفية الثقافية للمشاركين.

في المملكة العربية السعودية ، هناك بعض الأدوار والواجبات متوقعة من النساء بالأخص ،مما يعني تفرد الثقافة السعودية. ومع ذلك ، فإن خدمات الرعاية الصحية المتاحة لعلاج هبوط أعضاء الحوض ، مثل العلاج الطبيعي ، ليست مستخدمة بشكل جيد للغاية. هذا مؤشر على أنه قد يكون هناك شيء فريد في تجربة النساء السعوديات المصابات بالهبوط. ومن ثم، تهدف هذه الدراسة إلى استكشاف تجربة النساء المصابات بانخفاض أعضاء الحوض حول سن انقطاع الطمث وكيفية تفاعلهن مع خدمات الرعاية الصحية المتاحة لهن في المملكة العربية السعودية.

## ٢- لماذا طلب منى المشاركة؟

لقد تمت دعوتك للمشاركة في هذه الدراسة لأنك في سن انقطاع الطمث وتعاني من أعراض هبوط أعضاء الحوض ولم تحصلي عن علاج للحالة.

## ٣- هل علي المشاركه في البحث؟

الأمر متروك لك لإتخاذ القرار في الانضمام الى الدراسة. في حال الموافقة سوف تستلمين هذه الورقة التي تشرح لك معلومات عن البحث وإقرار خطي بالموافقة. وبنفس الوقت لك مطلق الحرية في الانسحاب في أي وقت خلال الدراسة، دون إبداء مبررات. ايضا في حال عدم المشاركة الان أو في المستقبل فذلك لن يؤثر على الرعاية الصحية التي قد تتلقينها في المستشفى .

# ٤ - ماذا سوف يحدث لو شاركت في البحث؟

اذا اخترت المشاركة في البحث فسوف يطلب منك أولاً ملئ إقرار خطي بالموافقة للانضمام للبحث. ثانياً الحديث عن تجربتك مع المرض في مقابلة شخصيه معي وجهاً لوجه للمدة قد تستغرق ما بين ساعة الى ساعتين لا أكثر . سيطلب منك أن تتحدثي عن تجربتك في معاناتك مع الأعراض و كيف تؤثر على حياتك و علاقاتك و نشاطك الاجتماعي، المقابلات سوف تقام في مكتبة الملك فهد العامة بجدة. علماً بأن هذه المقابلات سوف تسجل صوتياً لدر استها وتحليلها .

## ٥- ماهى المساوئ المحتمل حدوثها فى حال المشاركة؟

لا أتوقع أن يكون هناك أي مخاطر مرتبطة بالإنضمام في الدراسة ومع ذلك قد يكون التحدث عن تجربتك مع المرض موضوع حساس للبوح فيه. سوف يكون لديك الخيار في اختيار الأحداث المهمة في تجربتك في نهج سرد قصتك مع المرض. أيضاً سوف يعرض عليك إما تغيير السؤال لإداره مسار المقابلة أوطلب إنهاء المقابلة بدون ذكر أي مبررات .

# ٦- ماهي منافع اشتراكي في البحث؟

خطة متابعه علاجك لن تتغير سواء شاركت في البحث ام لا، أيضا لا أستطيع ان أعد ان هذه الدراسة سوف تساعدك لكن ثقي بأن المعلومات التي سأحصل عليها قد تفيد الاخرين في المستقبل. مع ذلك بعض النساء تجدن بعض الراحه عند التحدث عن تجربتهن مع المرض كوسيله علاجية. علاوة على ذلك سوف تساهمين في توضيح طبيعة حياتك وتجربتك الشخصية مع المرض. بالإضافة الى ان مساهمتك قد تتيح المجال لغيرك من النساء اللآتي يتقاسمن نفس تجربتك وير غبن في تحسين وضعهن الحالي عبر تغيير ثقافة المجتمع عن هبوط أعضاء الحوض. بالإضافة الى أن تقاسم تجربتك معي قد تساعد العاملين في مجال الرعاية الصحية لفهم احتياجتك وتلبيتها .

# ٧- هل مشاركتي في البحث ستكون سريه؟

نعم، جميع المعلومات الي شاركتي بها ستُعامل بسرية تامه. جميع معلوماتك الشخصيه مثل إسمك سوف تكون سريه ومجهولة للاخرين في عمليه تخزين المعلومات وتحليلها. بعد تسجيل المقابلات صوتياً سأقوم على الفور بتخزينها بحاسوبي الشخصي وحمايتها بكلمه سر. جامعه كاردف سوف تؤرشف المعلومات ثم تتلفها بعد مرور ٥ سنوات من تخزين المعلومات .

# ٨- من يعلم بمشاركتي في البحث؟

المشاركة في هذه الدر اسة هي طو عيه تماماً وأي معلومات لها علاقة في البحث سوف تُعامل بطريقه سرية تامه . المعلومات فقط سوف يطلع عليها الباحثة والمشر فات الأكاديميات على البحث من جامعه كار ديف في بريطانيا والمترجمة القائمة على ترجمة نصوص المقابلة من اللغة العربية الى الإنجليزية .

٩- من هو داعم الدراسة؟

الدراسة بر عاية الملحقية الثقافية السعودية في بريطانيا وايرلندا تحت مظلة وزارة التعليم العالى .

۱۰ من راجع ووافق على الدراسة؟

هذه الدراسة قد تمت مراجعتها والموافقة عليها من قبل لجنة اخلاقيات البحث العلمي في كليه العلوم الصحية في جامعه كاردف لحماية حقوق المشاركة في البحث.

بيانات الاتصال:

إذا كان لديك أي استفسار بشأن الدر اسة فلا تترددي في الاتصال بي

اسم الباحثة :فهدة محمد الشيخ

ايميل: AlshiakhF@cardiff.ac.uk

في الختام أتقدم بوافر الشكر والامتنان لمساهمتك الكريمة في الدراسة سائلين المولى عز وجل أن يجعله في ميزان حسناتكم ويوفقنا وإياكم لما فيه الخير لشعبنا وأمتنا .

مساهمتك في هذه الدر اسة محل العرفان والتقدير، شكراً جزيلا

### Appendix G: The idiographic experience

Aziza

Generated themes

Theme 1: Understanding of prolapse:

This theme demonstrate the causes Aziza attributed to pelvic organ prolapse. The causes she mentioned were a result of her own sense making as she indicated she had no prior knowledge. This theme also shows the implication of the condition on Aziza.

Aziza provided two potential causes for which she thought she had prolapse. The first cause was essentially provided to Aziza by her doctor a ,long time ago when she asked her what caused her uterus to prolapse.

"she said sometimes there happens a weakness in the tissues because of pregnancy and labour and more if it is difficult labour"

Aziza said the doctor linked pregnancy and labour to pelvic muscle weakness. But Aziza discussed during the interview that her last delivery was difficult and complicated. Perhaps she meant that what the doctor was telling her was relevant to her condition. Nevertheless, Aziza also attributed pelvic muscle weakness to aging:

"I don't know, how would I know? Maybe I have weakness in my pelvis from inside, that's it is son of Adam this is his age"

She acknowledged lack of knowledge. Her later response suggests that she thought it was impossible for her to know the definite causes of prolapse. Aziza then provided her possible explanations for the condition. She assumed that it could be because she might have pelvic muscles weakness due to the aging process. Aziza suggested that developing prolapse at her age might be perceived as expected. Linking prolapse to aging was a result of Aziza' sense making and interpretation of the world she lives in. Yet the way Aziza said this, and the use of words might reflect some deeper issues that are discussed under the theme religious beliefs. Providing two different causes for muscle weakness that led to prolapse suggests that Aziza thought there was no definite reason for why she thought she had prolapse rather she considered a number of risk factors that predisposed her to develop prolapse which demonstrates the complexity of her understanding.

Aziza then spoke about the implication of prolapse:

"I got panicked! When I first saw it I did not know what it was! I am telling you like a baby head, I was terrified!"

Aziza said that when symptoms started shewas fearful and she linked thisto another traumatising experience in the past: childbirth, which was terrifying to her because her last labour was difficult. But over time her feelings of fear were reduced, at times she indicated she was bothered by it and then she contradicted those feelings and said it was not bothering her even when it grew bigger. Couple of months later, Aziza started to feel that she has urinary symptoms that were disturbing to her.

"the urine started to come down one after another, it come and I get in the bathroom and get in the bathroom, and it continued so I came to the hospital here"

Despite the fear she had when she saw her uterus, Aziza did not see it as a concerning issue requiring immediate medicalsupport, possibly because she partially considered it a normal part of aging. But Aziza said that the frequent urge to urinate was the symptom whichtriggered her to seek healthcare support. It could be because of the different degrees of impact both symptoms have caused. The vaginal protrusion caused her fear initially which subsided overtime. But the urinary symptoms have impacted on her daily life in a number of ways.

Losing control over urination left Aziza afraid. The fear was of having sudden accidents, which resulted in her decision to wear diapers in order to hide her problem.

"I am scared! Scared of the urine! Look at me I am sitting with diapers

To further avoid having accidents, Aziza limited herself from going out to attending gatherings and she would wear diapers if she did go out to keep her problem hidden and avoid any embarrassment. Aziza did not wish people to know that she has no control over her bladder, and she ended up feeling isolated.

"the urine problem that have isolated me, I'm not comfortable in outings nor gatherings, if urine comes out of me what will I do? That's why I am using diapers."

She linked her sense of being isolated to her urinary symptoms not to her response to these symptoms. And despite desperately wanting to get back to her lifestyle: visiting religious sites and attending her gatherings, Aziza felt she must hide her problem.

"I am bothered by the urine meaning I want to go to Madinah, I want to go to the holy mosque, I want to go to my soirees that I used to go to, but nothing I cannot, as I told you I am scared, because son of Adam is veiled, he stays home its better for him."

The interpretation of what Aziza was saying perhaps was that her problem was personal to her and hidden from being seen particularly by her social circle, choosing to stay at home in order to hide it seemed better to Aziza rather than going out and embarrassing herself through having accidents. But saying "son of Adam is veiled" and her choice of words perhaps reflects a part of Aziza's religious beliefs

Theme 2: Sisters' experiences:

This theme is about the role of sisters in Aziza's experience. Aziza mentioned that she spoke to her sister about her condition who shared a similar experience with her and advised her what to do. Aziza did not speak about her other family membersin respect of her illness, and she refused to speak about the implication of her condition on her sex life when she agreed to take part in the study.

Soon afterexperiencing the symptoms of prolapse, Aziza spoke to one of her sisters who previously had prolapse and shared her experience with her.

"I spoke to one of my sisters she has an operation done for it, she has done two operations, my two sisters have done it! My sister (A) in Riyadh done it twice and now they have put supporters in her she does not want to do the operation again, now every two months she puts the supporter, and (B) no she has done it once and she is doing fine"

Talking to her sister demonstrates Aziza's willingness to share her experience with her family members. Aziza said that both of her sisters had prolapse and had sought healthcare support for managing it. It is unclear whether she knew about her sisters' experiences before developing the condition. Her sister has advised her to seek support for her condition.

"They told me to go to the doctor, I told them when this ball came down of me at first before I go to the doctor, but I told them that no I will wait a bit not now."

Despite being advised, Aziza chose to delay seeking support. It felt that she was not prompted to seek help by her sister's experiences nor by noticing a protrusion. An increase in urinary symptoms did prompt help seeking though. But there appeared to be certain personal factors that informed Aziza's choice of delaying seeking healthcare support that are discussed in the next theme.

Theme 3: Healthcare seeking behaviour:

This theme discusses Aziza's healthcare seeking behaviour. She delayed seeking professional help but was prompted to do so as soon as she started to experience urinary symptoms. This theme presents the reasons for which Aziza justified her reluctance to seek help and her experience of seeking help.

Aziza said that she did not seek immediate support even after her sister advised her to do so and her reason was that she was reluctant as she did not wish for anybody to see her.

"I don't know, I swear I was mentally reluctant, I did not want anyone to see me" Aziza said she was "mentally reluctant", her choice of words was interesting and could allude that she was aware that her body was in need for help, but mind was resisting. And by saying "see me", Aziza might mean medical physical examinations. She perhaps did not want to have any assessment and perceived it as if someone would see her private body parts. she Sdescribed two conflicts, seeking help and maintaining social contacts, or tolerating symptoms and avoid ingpeople. Her discourse suggests that prolapse was a personal and private issue to her, and physical examinations would mean invading her privacy.

Aziza later spoke about her experience with healthcare for a past shoulder injury. She said she had to be seen by many doctors until her shoulder was treated. And this experience caused Aziza to have concerneds resulting in her being reluctant to seek help.

#### "I was afraid of being exposed and exposed from doctor to doctor"

Aziza used the word "exposed" to talk about her concerns of being seen by physicians during examination. Her use of language suggests that she was rather more concerned about having to undress and show her private body parts. Indeed, Aziza has indicated that the location of the problem was concerning in terms of being exposed repeatedly

"You know this problem one would not want to be exposed every time! I mean, you know where it is!"

Hence, not being physically examined was a priority for Aziza. She had the willingness to tolerate prolapse symptoms until they got intolerable anymore and she was in need for professional help.

The issue of being exposed was recurring when Aziza eventually decided to seek support, but her discourse suggests that her experience has not been pleasant. It was decided for Aziza to have surgical lifting and she was about to have the surgery but this was delayed for external reasons. Since then, Aziza has been seen by three different doctors, and in her own perception, she was exposed repeatedly. "I have exposed and was about to do the operations and it was delayed, and them came back to be exposed again."

Aziza felt that she has been by so many doctors so far for her prolapse.

"look how many doctors until now have seen me! That's it I became like charity: exposed to everybody"

Azizaconsidered that she is doing the doctors and healthcare professionals a service by allowing them to examine her. She has followed her sentence with a laugh, and she was perhaps being sarcastic about her experience that she was concerned of being seen by doctors due to the sensitivity of her condition but ended up being seen by three or more doctors and feeling repeatedlyexposed. Prolapse was a personal problem to Aziza and thesense of being exposed perhaps reflects the distressing emotions that are originally associated with her showing her body parts, specifically this part of her body, given that she is a religious woman.

In her last attempt to have the surgery, Aziza was all prepared and triaged to enter the operation room but was told that her surgery was cancelled as the doctor did not attend.

"I came and slept here, and they put me on the feeder and brought me down to the operation room and the doctor had given me the anaesthetic needle for the anaesthesia. Me and my family sat there waiting and at last they told me that the surgery has been delayed, why my dear? They said she did not come"

As she returned to her room, the resident doctor asked her to go back to the triage room so she could have the surgery. But Aziza refused saying she was not feeling mentally well.

"I told him no I can't enough I am not feeling "mentally well""

Aziza said this experience caused her to feel distressed and this possibly could be because she was already concerned of being exposed to many physicians and she was overwhelmed. Aziza in fact has said that vaginal examinations have been so tiring to her.

# "And every time someone comes to check on me I get so tired, I feel myself very tired from down there."

She indicated she felt tired with examinations and then said she had no pain during the process but explained her tiredness as sense of being mentally unwell. It seemed that the tiredness Aziza was referring to was perhaps the mental distress she has been feeling each time her prolapse was assessed and examined.

"Tired meaning mentally unwell enough! It doesn't hurt me, pain I don't have"

When narrating her above experience of delayed surgeries, Aziza was repetitively using the word "they" and saying, "they delayed me", "they put", "they took me". There was a passive sound in her overall experience with healthcare. This further emerged when Aziza told the doctor "I am between your hands" which suggests that Aziza did not wish to be involved in managing her own condition.

"the resident doctor came and told me why are you late? I said how would I know? I am here between your hands!"

What Aziza said here shows some level of contradiction, she declines treatment but also allows doctors to make decisions for her stating that she is in their control. Moreover, when the doctor was explaining the surgical procedure to Aziza, she responded:

"she told me that she will lift and suture and do and tight and she was explaining to me, but my dear daughter I am not a doctor to understand, I told her I am between your hands, what you want do it"

Aziza refused to participate in her treatment plan justifying her response by saying that she was not a doctor. She started off by saying that she had a similar experience of having a corrective surgery after having her second child so assuming that she had a brief understanding of the process is acceptable, yet she denied having any understanding and sounded passive by telling the doctor to do whatever she wished to do and accepting her advice even if she thought she did not need it. She further said the doctor gave her medication for something that she did not believe to be a problem and she took it anyway.

"she said she will give me medication for constipation, although my tummy is always fine but I yet take the medication"

But her experience of healthcare support and being delayed for more than four months caused her symptoms to regress over time, particularly her urinary symptoms.

"Now few days ago I was looking and it became this big (fist), the uterus is descending, now the urine sometimes when I am sitting, sitting like this, I just stand up and I see myself all wet, without me feeling of course, see I can't go to the holy mosque, I can't travel to Medina, I can't go to my soirees, nothing!"

The prolapse increased in size and she lost control over bladder. The lack of bladder control seemed to be impacting Aziza the most as it adversely affected her lifestyle. She was no longer able to visit the religious sites because it required her to be clean and passing urine in these sites is religiously unacceptable.

#### Theme 4: Religious beliefs:

This theme represents Aziza's underpinning religious beliefs that were central in her experience and impacted her rationalising for her condition and also her response towards her illness and the decisions she made.

Aziza has used the words "expose" and "hide" interchangeably. She did not wish to be exposed to physicians during assessment, and also wanted to hide that she had no bladder control. There seemed to be an impulse to cover herself physically and morally that was perhaps rooted in Aziza's religious belief. Aziza referred to mankind as "son of Adam", from a religious perspective Adam was the first human God created. It was indicated in the Islamic holy book that God ordered Adam to cover his private body parts when he was sent to earth from heaven. And this seemed to be the natural order of things to Aziza, she perhaps thought she was obligated to keep her private body parts covered as she was a descendant of Adam, which was preventing her from seeking herself and being examined.

Islam asserts the necessity for women to cover their bodies. The obedience of women to this rule correlates with how strong their religious beliefs are. Therefore, it is acceptable for some women to expose their body parts, especially private areas, for various purposes relevant to healthcare, while other women find it difficult particularly if they had to do it many times because it goes against their belief. Aziza's discourse suggested that she was a religious woman with strong beliefs, it might be less hard for her if she had the desired support from her first visit to healthcare but moving between multiple physicians perhaps contradicted her belief on the urge to cover her private parts repeatedly.

In terms of cover self morally, Aziza said that "son of Adam is veiled" in the context of hiding her lack of bladder control. She meant that all mankind has different issues that are supposed to be kept hidden and Islam advises people not to talk negatively about themselves or mention their flaws in front one another even if it was in front of close friends, this includes physical issues such as in Aziza's case.

Being passive to healthcare also seemed to be reinforced by her religious beliefs. Despite being in mental distress and her symptoms gotetting worse after her healthcare experiences, Aziza came for support three times. It could be assumed that it was because she was in need for help but there was also some acceptance of what happened so far as her destiny.

"God choose what is good my daughter. Meaning the operation was written for me and at last it comes and change and the rest is for God. Whatever our lord has written for me going to happen by the way."

There is a common religious belief that anything happens to one has been written for him/ her even before he/ she was born; and therefore, one should never fight back destiny or question why it happened. Indeed, difficult conditions are perceived as testing method for one's patience and strong beliefs. Aziza considered that she was destined to have prolapse and she chose to accept what happened to her so far, including the cancelled operations, as her fate which might justify her passive response.

When Aziza rationalised prolapse as a result of pelvic weakness, looking at it as God's will was also emerging as it felt that she has accepted this as part of aging because she saw this as relevant to human life cycle.

The unpleasant experience Aziza had with healthcare for her shoulder problem was distressing to her, it was not useful for her. Aziza seemed to believe that they have made a moral mistake and asked God to forgive them.

"I went from doctor to doctor to doctor until king Abdullah hospital did analysis to me and referred me to physiotherapy and I did not benefit anything, may Allah forgive them"

She did not say that she forgave them despite being disadvantaged rather wanted god to forgive them. But this phrase is also often used if one is unhappy with a given person's behaviour, some might curse in similar circumstances and some might say "may Allah forgive them", particularly if they were religious like Aziza.

Aziza's first attempt of having the surgery was cancelled as her doctor was unwell, Aziza was praying that God helped her.

"May God help her; I am begging him with the stature of the prophet"

Religiously, the prophet Muhammed has a great status in Islam. It felt that Aziza wanted her to be healed of her illness by praying to God. Maybe Aziza was also praying for herself to get well or to have better experiences with healthcare because when she was asked about her expectations from healthcare she said:

"May Allah writes the good for me my daughter, nobody knows what is written at our lord's. Praise to god."

## Conclusion

The religious beliefs Aziza holds greatly informed her understanding and responses towards her illness. Difficult childbirth and aging were perceived as risk factors for prolapse suggesting that prolapse given these two risk factors is inevitable. Prolapse caused Aziza to have a couple of symptoms which progressed overtime and caused her to have urinary issues. The implications of loss of bladder control were more significant than prolapse to Aziza; therefore, she decided to seek professional help after losing bladder control. Before that, Aziza was reluctant to seek help despite her sisters advises and her reason was fear of being exposed. She was listed for surgery three times makingand the resultant delayde her symptoms regress and feeling exposed.s of frustration highten due to repeated and unnecessary

Dina

Generated themes

### Theme 1: Understanding of prolapse

This theme represents Dina's understanding of prolapse, it discusses Dina reasoning for the condition and the way she perceived it has affected her. Dina has not spoken about the causes of prolapse in great depth (except for housework, and this is further discussed under the theme "control"), but she spoke deliberately about how living with prolapse has affected her over four years significantly. Consequently, it could be perceived that the effects of living with prolapse were more concerning to Dina rather than the prolapse itself.

Dina has given three reasons for why she thought she had prolapsed, which were; family history, spacing between childbirth, and housework.

"I don't know, maybe it is hereditary? My aunt was like this, and they just removed her uterus, but I don't know if its hereditary or if it because of frequent labours that happen one after another, I mean I have 6 children and they were all close, I mean there were only two years between each delivery and another, it might be because of pushing during delivery maybe, maybe from housework, I was really exhausting myself"

She begun by acknowledging first that she did not know why it happened to her. And then she provided her perceived causes whilst indicating that she was uncertain by saying "maybe" and "might". Justifying her condition and linking it to certain factors that were usual to her, perhaps reflects that Dina thought of prolapse as something rather expected because she has been involved in heavy house duties, had six children with two years between each delivery, and because her aunt also had it. Despite her uncertainty of the causes, the risk factors she mentioned seems to be significant to her, particularly, housework and pregnancy. Dina spoke about these two reasons a lot during the interview and gave her explanation of how she perceived it might affect her. As she had a baby every two years, Dina thought this has negatively affected her uterus and she perhaps was regretting this at this stage. And in terms of housework, her discourse suggest that she has been involved in housework most of the time and now started to feel that it has adversely affected her health.

Dina felts prolapse affected her on multiple levels, there were physical changes in her vagina in form of protrusion and she said that she often noticed that her vagina was coming out when she used the restroom. There were further psychological consequences as she was afraid when she felt or saw it out, and it made her feel sick at times.

"I am scared of it, I am really scared of it, when I see it coming out, I just don't want to do anything, I am afraid that it all might fall out of me!"

She was afraid as she felt that her uterus might fall out her causing her to feel that she does not want to be involved in any work. Due to the consequences of prolapse, Dina said that she felt she was no longer able to maintain her responsibilities towards her family. Because she felt sick and afraid, she was not able to do any house chores, look after her family and cook for them.

"I am not capable of doing any work, I can't do anything, I am scared I mean that's it I can't do any housework like cooking and so, no I can't!"

She was repetitively saying "I can't" and "I am uncapable". Dina felt her role within her wider family was also affected, they visited often and she had to prepare the house and show her hospitality skills, this is further explored under the theme

"family". Her condition seemed to make it harder for Dina as she felt sick and tired when preparing her house for guests.

"and his family are always visiting us and we have guests frequently, and you know there is housework and so on, now even the preparations make me sick"

Dina felt that the condition also affected her marital relationship as she felt she was unable to have intercourse with her husband.

"It even affected the relation; I mean sometimes he approaches me, and I tell him I am sick"

The inability to have intercourse did not seem to be directly linked to physical symptoms of prolapse, as Dina has said that she had "no desire" for sex but it could be a form of psychological consequences i.e., fear. Dina indicated that she felt afraid each time her husband wanted to have sex because she was concerned that she would end up injuring the uterus, which has happened before, but Dina did not say if the injury was resulted from sex or something else.

"Every time I sleep with him, I get so worried yes that it might be raptured again, I don't feel comfortable when I do, I feel nervous."

Dina's discourse suggests that it was not the prolapse itself that was bothering but it was the consequences of prolapse or the implications that were disturbing and made her feel sick. The effects included the physical symptoms of prolapse and also some psychological consequences. As indicated above, the effects of living with prolapse have greatly interfered with Dina's roles and commitments to her family, close and wide.

### Theme 2: Family:

This theme discusses Dina's role within her family and also where her family stands within her experience of prolapse. The effects of living with prolapse were broadly overlapping with Dina's roles and commitments to her family. Family, indeed, was central to Dina, and her experience with prolapse somehow revolved around her commitment to her close family: her husband and children, and also her wider family or relatives. Dina's family have formed her social circle where she could share her concerns and would seek advice for her health-related problems.

Dina perceived her commitment to her family as a part of her identity, she begun the interview by identifying herself as a *"housewife"*. Dina seemed to be surrounded by her family perhaps for as far as she has known, her children were staying home even if they were in their twenties, and she was looking after them. Moreover, her family and husband's family visited Dina quite often:

"and his family are always visiting us and we have guests frequently"

Dina has not spoken whether she had any close friends outside her family; therefore, it can be assumed that Dina's family became her close social circle who she can share her concerns with or even talk to them about her health problems and they would advise her what to do about it. Dina spoke to her husband first when she started to feel ill, and he advised her to seek healthcare support:

"When I first told him that I have this descent, he was always arguing with me to go to the hospital"

Similar response was given by her wider family when she also spoke to them about what she has been feeling as they asked her what was wrong with her when she seemed ill:

"See when my family saw me sick, they were asking me what's wrong with you? what's wrong with you? I used to tell them that there is something like a ball coming out, I didn't know it's my uterus that is coming out ... my sisters shouted at me, she is older than me, that this is your uterus go to the hospital!"

Her family had responded to her illness through advising her to seek healthcare support, and her relatives shared their experiences with prolapse with her and provided her with information about the available healthcare support based on their experiences and what would be the best for her:

"One of my relatives had it before and then she did an operation to remove the uterus."

#### The relative apparently was her aunt. Dina further added:

"Because there are lots of people, they say they have done an operation but did not remove the uterus, but it hangs just for 5 years, 5 years and it comes out again. I don't want it like this, I mean now I do the operation and then wait to do it again? I really don't want this, because I know someone who has done the operation without removing the uterus and it came out again."

Dina indicated that she first did not know what was happening to her, it might have not occurred to her that her problem required healthcare support until her family advised her to do and some shared their previous experiences with prolapse with Dina. She was informed that there are two methods for the management of prolapse: surgical lift and hysterectomy. Dina was more inclined towards hysterectomy as she was told that the effect of surgical lift is limited to five years. The information they shared with Dina affected her behaviour towards healthcare support. Her decision of healthcare was informed by the information she was provided from women in her family.

Theme 3: Healthcare seeking behaviour:

This theme represents Dina's overall behaviour towards healthcare support and the potential factors that might have led her to end up avoiding seeking healthcare. Dina avoided seeking healthcare support for any problem in her reproductive area for four years despite feeling very ill and uncapable, and she coped with her condition through self-managing the symptoms. Dina had no prior knowledge about prolapse nor about the treatment options, but the information provided by her family members perhaps shaped Dina's healthcare seeking behaviour due to fear of potential surgical intervention which was based on her past experience with healthcare.

The information Dina's family gave her became part of her knowledge. It appeared that she shaped her decision of healthcare based on the information that women in her family shared with her:

"Yes, this is the solution I think is suitable"

Dina thought hysterectomy was the suitable management plan for her condition based on what she has been told. The knowledge she had however seemed to be insufficient as Dina was further asking about the process, but her questions could also be explained as fear because the knowledge she gained about management approaches, rather than comforting her that there was a solution for her problem, had left her scared of approaching healthcare. Dina said she was *"scared of something called operation"*, she had two previous experiences with healthcare where she thought it disadvantaged her health, which was possibly the source of her fear:

"They were all normal, all easy except for the last one it was difficult. I was so sick, the doctor told me don't walk don't move and I listened to her, so I started to have contractions and the girl wasn't yet down to the pelvis yet that's why poor thing she had low oxygen. But in all my pregnancies there was cutting and suturing, with my eldest daughter she is 28 now, I was really sick when I had her because the nurse forgot the gauze inside me and sutured the tear that they made and forgot the gauze inside "

Dina thought she was given poor advise in her last labour that resulted in her daughter being born with a disability. Another incident was in her first delivery as the doctor forgot a gauze inside her uterus following episiotomy. Dina thought she was disadvantaged by healthcare twice and she ended up avoiding seeking healthcare support even at times she was sick and was in need for it. These two past experiences might have caused Dina to have negative expectations from healthcare and she had lost trust and confidence in healthcare professionals.

"I am stubborn I don't like the (Pause), during summer when we were at ... I got so sick there and I said no way that I go to the hospitals there."

Dina referred to herself as stubborn as she would not seek healthcare support even in times of need, particularly for problems in her reproductive area. Therefore, Dina has set few terms or necessities if she decided to approach healthcare: "I don't like to go to any hospital or any doctor that I am not familiar with, I feel I only want the doctor who I always see, depending if I feel comfortable with him or her, I mean I only go to the doctor who I am comfortable with, you know I told my endocrinologist that please refer me to a gynaecologist that you know and trust and feel comfortable with"

Dina said she preferred seeing doctors who made her feel comfortable or doctor she was familiar with, and this seems that she might wanted to ensure that she was between safe hands and would not be disadvantaged again. Nevertheless, she might have set those terms to make things complex for herself so the easier option would be to simply avoid healthcare. Hence, Dina has chosen to avoid seeking healthcare support for any problem in her reproductive area, not only prolapse, because she did not wish to have any similar incidents:

"This was a year ago and I used to use antiseptic, the vaginal douche, to disinfect the wound so nothing happens to it, I also fill the tub with warm water to sit on it. It was gone few months afterwards."

self-managing her symptoms or the condition all over has been her way of coping and also avoiding healthcare, she has done so when she had a wound in her uterus, and she decided to use antiseptics, vaginal douche and warm water baths rather than seeing a doctor. In terms of prolapse, Dina said she would lie down and rest if she felt she needed to.

"When I see myself feeling sick go and lie down, until I feel relieved and then get up and do the things that I want."

Dina found rest to be relieving when she felt sick, and because she noticed that she often felt sick when she was involved in her responsibilities towards her house and family, Dina has decided to step back from those responsibilities and take an "open vacation".

"but when I am resting and lying down there is nothing, that's why I said when I am lying down and resting I feel fine so I am not doing anything from now on"

#### Theme 4: Control:

The theme "control" has emerged as Dina spoke about how she decided to step back from her responsibilities and take action. The theme represents how Dina initially thought she lacked control over her life by overdoing housework and was controlling her condition through self-managing the symptoms in order to cope, but later on she took control over different aspects of her life.

Based on the decision Dina took, it seemed that self-managing the symptoms of prolapse through rest has become the source of control for her. She was initially coping with her life in the presence of prolapse through controlling the symptoms, she would take rest when she felt ill, and would return back to her responsibilities once the symptoms ease. She has been involved in housework for so long and has tried maintaining her roles withing her family even after developing prolapse. Dina has indicated no previous self-control when it comes to housework.

"I mean at first at first (Pause), I used to exhaust myself, I didn't have mercy on myself, I used to do this and do that and do so many things, and then I started to have some bleeding with it, very small amount when I am standing"

The word self-mercy has been used repeatedly by Dina and it might reflect that she has been doing intensive housework. And after developing prolapse, housework has further made her condition worse as she had occasional bleeding with it. Dina has provided a metaphor to further assert that she has been involved in heavy housework, she said:

"I used to strain myself with hard work, I have no self-mercy, if there was a maid doing what I was doing she would have escaped because of the hard work I used to do"

Dina said if she had a housemaid and was assigned to do the work Dina has been doing at home she would have escaped, which probably meant that she would not do it as it was intensive housework. To further elaborate on the type of work she has been doing, Dina further continued:

"Anything you can imagine, I spent most of the time standing on my feet, cooking washing and cleaning throughout the day I had no maid or anyone to help, do you know the gas cylinder? I used to carry and change it; I have exhausted myself too much and now here I am."

It appeared that Dina was somehow back tracing the work she has been doing linking it to how it caused her to develop prolapse, while taking the blame and owning the responsibility to herself that things were not under control:

"I am telling you I blame myself for this, if I haven't done all this or if I have said no maybe I would have this problem, but I totally consumed myself."

But after four years, Dina might have felt it was time to take control in order to limit the symptoms or the effect of prolapse on her, she begun by stepping back from her responsibilities as a housewife and a mother:

"I have stopped I told them that's enough, I am sorry I no longer can do anything, I told them I am not going to do anything for you, if anyone wants something he or she can buy it or bring it from any shop"

Similar action was taken towards her wider family. Dina was no longer involved in housework, and as she perhaps was not in place to refuse having guests, she asked her husband to bring takeaway food as she would not cook for them:

"I told him I can't, if you want to invite them then bring or buy something from any restaurant, so he started to bring food from restaurants when he invites them"

Taking control also involved her intimate relationship. Sex seemed to bring a lot of concerns and worries to Dina, and to further control the psychological effects of prolapse, Dina has given her husband the approval to seek another wife because she was uncapable to sleep with him: "I told him to go and get married but he refused, he wronged himself (Laugh), anyway I told him I am sick and no longer capable of this, if you want to get married go get married, he refused!"

Telling her husband to seek another wife might be a form of controlling the feelings of guilt that resulted from her not having intimate feeling for her husband.

"I am sick, I feel nothing I don't have any desire, but I feel sorry for him, that's why I gave him my permission to get married if he wants."

The decision to seek healthcare support after four years and participating in my research might also be viewed as a form of taking control over her condition and finally find a solution.

Nevertheless, Dina was repetitively asserting self through saying "*I told them*" throughout the interview. At times it felt that it might be because she was contradicting her own belief by stepping out of her responsibilities and taking action or she possibly had to inform them that she was going to stop doing what has been expected to do for a long time.

Theme 5: Cultural and religious perspectives:

This theme represents Dina's belief system and the potential role of culture in shaping her experience with the condition. Dina and I shared the same cultural background and her interview broadly reflected certain cultural and religious aspects that are common in Saudi Arabia.

To begin with, Dina narratives suggested that there were certain gender role norms and different expectations from men and women. Housework and holding receptions were parts of expectations from women:

"I also went to ... city in summer holidays, and I saw all our family there and you know each woman has to do a reception and invite the whole family home and prepare a feast" And because they are expected to be involved in housework, Dina might thought that women often subconsciously do too much housework, and she herself had no control over it:

"I mean we women work work work and we don't notice that we are exhausting ourselves and it is affecting us, so you don't do that"

Although Dina had mentioned three potential risk factors for developing prolapse, she spoke a lot about housework. Family history was out of her control, and in terms of pregnancy, Dina thought of spacing between children as predisposing factor not pregnancy and labour itself. This perhaps indicates the influence of her cultural and religious beliefs as some societies in Saudi Arabia value big families and having a lot of children is viewed as a privilege.

Similar to women, Dina narrative suggested that there are certain roles for men in the family. Dina's husband's response to her illness changed over course of events, he first advised her to seek help when she told him about her problem which she refused, then she thought he expected from her to maintain her roles despite her being sick until he seen a proof of illness that changed his response towards her illness:

"Well, he became so worried and concerned about me, one day I fainted, at the beginning he was a bit"

Being a man, it appeared that Dina's husband acquired a superior position in the family, giving him the eligibility to be broadly responsible for his wife. Because he has maintained his dominant role in the family, Dina thought it would be unacceptable for her to resign or refuse his commands although she had health related problems other than prolapse:

"anything my husband asks me I would do it, even if there is a feast at home I used to prepare it all myself I never said I can't. I never liked saying no to him for anything, he also never said no to me for things that I ask, he would do anything I ask him to, so why would I rebel when he invites his family?" Dina indicated that her husband did not mind her maintaining her roles within the family despite her illness, but later on he became understanding of her condition asking her to rest. Her decision to take control or take an "open vacation" was perhaps following his approval of her illness:

## "he is understanding that I am sick, praise to God"

Dina was thanking God because her husband finally understood what she has been going through. Dina's religious beliefs were brought under light particularly at two opposite conditions: at times when she was being grateful or while sharing distressing information. She was grateful that her husband understood her condition, and that her in laws love her. But she was perhaps distressed when she was explaining what her prolapse looked like and while mentioning that her daughter had a disability.

#### Conclusion

Five themes were generated out of Dina's transcript, namely: understanding of prolapse, family, healthcare support, control, and cultural and religious perspectives. There was no theme superior to other rather they were all connected and overlapping. Dina's understanding of prolapse and her rationalising for the condition and how it has affected her was relevant to her role within her family and her commitments to them. As her responsibilities towards her family was a part of her identity, Dina has shared her concerns and gained much knowledge about prolapse from her family. This has shaped her healthcare related decision that was already informed by past healthcare experiences where she was disadvantaged. Dina avoided seeking healthcare support and chose to take control instead mainly by taking an open vacation. Yet this was contradicting her inner belief that was largely influenced by her cultural and religious perspectives.

Lilly:

Generated themes

Theme 1: Understanding of prolapse:

This theme discusses the causes for prolapse as perceived by Lilly and the control she had over these causes. Lilly felt she had no control over the causes she mentioned rather it was controlled by her parents and the society; therefore, thought having prolapse was inevitable. But Lilly was hoping to help her daughter to avoid it through controlling some of her choices.

Lilly spoke about the reasons she thought she developed pelvic organ prolapse. The reasons were: heavy lifting, pregnancy and labour, and early marriage. Lilly said that she has been involved in lifting heavy objects around the house intensively.

"I suppose it because of lifting, (Pause) we don't have mercy on ourselves, we would carry anything, a fridge, a gas cylinder. Even pregnancy and labour have a role."

Lilly here was speaking about lifting heavy things in the context of herself and her sisters, and the effect it had on them by causing them all to have prolapse. When Lilly said that they did not have mercy on themselves, she was aligning her experience with that of others. It could also imply that lifting heavy objects around the house was expected from her as a housewife and part of her responsibilities. Lilly also indicated pregnancy and labour as a cause for prolapse and shared her perspective, she said:

"Pregnancy and labour have effect, I got tired with every labour, each pregnancy and labour is different, they say the uterus sags, at the time of labour at the time of pushing of course the uterus drops"

Lilly asserted the impact of pregnancy and childbirth on developing prolapse while indicating that she felt tired after each delivery. She was certain that childbirth was a causing factor for prolapse. She had been pregnant eleven times, including three miscarriages. She explained how prolapse was relevant to her frequent pregnancies; however, Lilly said she had a new-born every two years:

"not like every two years I had a new born"

While this could be her personal choice, but how Lilly has expressed it and her tone of voice when she said this could suggest some deeper issues; it could be that she had no control over it as it was a part of her expectations as a woman. Lilly then spoke about the effect of early marriage on reproductive health.

"early marriage has damaging effect, when you are young its different than when you are an adult."

Lilly said that early marriage has damaging effect, she was not precise what the effect was or what was being affected but considering the context of her narrative it appears that she was referring to her uterus. Lilly then rationalises early marriage as a potential cause for prolapse, it seemed that sex may have been what Lilly was referring to. She might be talking about it this way as she perhaps was not comfortable mentioning sex in relation to early age marriage. Lilly said she and her sister got married and perhaps had sex at a very early age which Lilly felt it had also caused them to develop the condition.

"my older sister got married at 8 can you imagine !! a child !! if you get married and haven't had your fist period yet it is so hard, deadly hard !! not like when you are an adult, it definitely affects the drop."

Perhaps Lilly meant that having sex at this age even before reaching the age of puberty is hard and considered it a reason to develop prolapse. But she said her sister was the one who got married when she was eight years old, Lilly got married when she was fourteen years old. She did not mention if she has had her first period around that age though.

Getting married at early age also seemed out of Lilly's control but she felt it was entirely the parents' decision. Hence, it deemed appropriate for Lilly to control her daughter's marriage and her aim perhaps was so she could avoid developing prolapse.

"I got married when I was 14, but I don't arrange my daughters" weddings unless they are 24 25 years old, we used to get married at 13 14, (Pause) my sister got married when she was 8!" Given that Lilly thought early marriage, which was apparently under the control of her parents, caused her to have prolapse she decided that she will arrange her daughters' weddings after ensuring that they are at appropriate age. Her experience has indeed shaped the decision she made.

Lilly has provided the causes for which she perceived has caused to have prolapse and she has spoken deliberately about and gave her explanation, and this suggested she had some knowledge about her condition, the following theme discusses the knowledge she has about prolapse and how she has developed it.

Lilly seemed eager to develop her own understanding about prolapse through constant reading. Regardless of the accuracy of information she had, Lilly seemed to be confident in what she read as she spoke about the reasons for why she thought she and her sisters had prolapse.

# "I always read; I'm not philosophising you"

She did not mention the resources she gained her information from but she felt that it has increased her knowledge about the condition. Lilly was also frequently questioning why certain things happened to her, for example, she said that after miscarriage and uterine cleaning, her period was affected, and she questioned why it happened. Menopause and prolapse were considered potential reasons for her affected menstruation cycle.

"I don't know whether I have reached the age of menopause "desperate age" or it's because of the drop"

Lilly identified menopause as "desperate age", this is explored under the theme "cultural and religious perspectives". Lilly said that her symptoms got much worse after miscarriage, and she also was uncertain of the cause. And it felt that she thought of uterine cleaning done by a doctor to be responsible for making it worse.

"Problem was worse after the miscarriage, I don't know why, maybe it was the cleaning afterwards"

Lilly then also questioned why she no longer had desire for sex, and she was thinking about prolapse or the pain she was having as possible reasons.

# "You no longer desire this thing, it dies, the libido, it ends I don't know how, (Pause) is it the pain, is it the drop, I don't know."

Lilly separated pain from prolapse and did consider the possibility that prolapse and pain together could be the reason for her disturbed sex life. Nevertheless, she indicated she reads a lot, and she thinks about the causes of prolapse and questions many things, but she did not appear to relate the knowledge she has to herself. This was also evident as she spoke about her urinary symptoms.

"At the beginning urine used to come out without me feeling it. I sneeze, it comes out, I laugh, it comes out, and then this stopped when my uterus dropped and pressed on my bladder blocking the urine

passage"

Lilly said that her urinary symptoms at first started off as lack of control over bladder and this has progressed as her prolapse was progressing, or in her own words, it blocked the urine passage. As a result, Lilly was no longer passing urine with every sneeze and laugh; thus, she perceived that she stopped having this particular problem because she no longer felt urine coming out of her uncontrollably. She mentioned that she was told that there was a chance that she had urinary incontinence and has done some tests, but it was not confirmed that she had UI.

"they told me maybe you have urinary incontinence, praise to God. I have done some tests but I don't think it was urinary incontinence, they would tell me if it was urine incontinence."

Lilly felt she needed a diagnosis to explain her symptoms and confirm her problem. It is possible that she did not know what urinary incontinence symptoms are or maybe she knew but, similar to other issues, she did not relate the knowledge she had to herself. This also emerged when Lilly was speaking about lifting heavy object around the house, she said that she had no self-mercy, and she had no control over it. But Lilly said she understood that it has been negatively affecting her health, but as she was so immersed in living her life, she did not think that it would have any effect on her.

# "when you are healthy praise to God you don't feel, you don't think it would affect you"

She has identified that prolapse was not something she considered or thought that it would ever happen to her, this perhaps could explain why she did not seek healthcare support immediately after having the condition and got pregnant after she did. Similarly, when talking about pregnancy and how she thought it led her to have prolapse, Lilly said she knew for a long time that pregnancy and delivery was a risk factors for prolapse, but she got pregnant eleven times and did not relate her knowledge to herself or consider that it would happen to her.

"Since very long time, but I never thought about it or relate it to myself, labour after labour is tiring, but if you wait like 7 years and had one child not one after another after another"

Moreover, Lilly got pregnant again after having prolapse but this pregnancy ended up with miscarriage. Even following this experience, Lilly said she did not relate the knowledge she had about the possibility of having prolapse to herself. Lilly did not say if she considered of her last pregnancy as a possible reason for making her symptoms worse, but instead she was thinking about miscarriage and uterine cleaning as potential factors and was questioning what was more likely to make her problem worse.

#### Theme 2: Family:

This theme represents the position of family in Lilly's experience. Lilly spoke about her sisters and prolapse as common issue between them, which perhaps justifies her concern about her daughter. Lilly also spoke about her husband and his response towards her illness and how it has affected their relationship.

Lilly has indicated that all her sisters had prolapse, she has spoken about why they all ended up having this issue and this has been discussed in the theme above.

"all my sisters in fact have a drop."

Prolapse was a common problem in Lilly's family; hence, she and her sisters had given it a specific name. Instead of saying prolapse, Lilly has used the word "drop"

frequently and it felt like a diagnostic term that she and her sisters used when they identify any potential prolapse symptoms. Lilly's sisters might have shared their problem with prolapse with her, and Lilly shared her experience with her sisters as soon as she started to have the symptoms and her sister asserted that it was the "drop".

"I told her what I have and she has been telling me that it's a drop drop drop"

When speaking about early marriage as a potential cause for prolapse, Lilly said she would not arrange her daughter's wedding unless they were in their midtwenties, and this perhaps was to help her daughter to avoid prolapse caused by early marriage and sex. Yet despite her attempts to control her daughter in order to help her avoid the condition, Lilly thought that her daughter has already developed prolapse.

"by the way girls can have this drop too not just old women. Girls who heavy lift, play intensive sports, my daughter always complains of her back pain, I tell her maybe you have a drop because of heavy lifting. She is 24."

Lilly said her daughter played intensive sports in the gym and lifted heavy weight, maybe Lilly did not have much control after all over her daughter's life to stop her from lifting heavy weight but as a parent she thought she was allowed to control her daughter from getting married at young age maybe because her own parents did. It seemed that she wanted to control what she could as a parent to maybe help her daughter to avoid the condition. But my mentioning her daughter and relating her backpain immediately to prolapse without considering any other factors, it felt as if Lilly was concerned about her daughter's health, and this could possibly be because prolapse was a common issue in Lilly's family, her concern was indeed informed by her own experience.

Lilly felt that prolapse had a direct implication on her marital relationship, particularly her sex life. Lilly said that her sex life was greatly disturbed since she had the symptoms.

"It became pitch "extremely bad". (Pause) It was so different before. Since I had the symptoms and I no longer accept this thing, I can't anymore. (Pause) Its too hard for me, you have a pain you can't, (Pause) I escape for 3 or 4 months"

By saying "it was different before" and comparing her sex life before and after having prolapse suggests that she was happy with her sex before having the condition. And after developing the condition, Lilly said that she would escape for a couple of months, it seemed that she meant that she avoided sex at times. This might indicate that she broadly had an active sex life but perhaps refused to sleep with her husband quite often. Her response towards her sex life and avoiding sex seemed to be driven by her husband's response, Lilly said her husband was patient with her.

## "I feel he is weak; I mean he is patient"

It felt that she would have acted differently if she thought of her husband as a less patient man. His patience was seen as weakness to Lilly. She said her husband would tell her to seek healthcare support and this suggests he was understanding and concerned about her health and that he did not force her to maintain active sex life in the presence of her illness, yet this was translated as weakness.

"Sometimes he feels sorry for me when he sees me crying and says enough "its ok, I don't want to but you have to go to the hospital", and he takes me to the hospital."

Lilly's view on her husband's response might be because she seen different responses from her sisters' husbands or maybe this is related to certain gender ideologies that are later discussed under the theme cultural perspectives. Nevertheless, because of her avoidance and her husband's understanding of her condition, Lilly felt that they were growing apart.

"but currently he is on one side and I'm on the other, the lust dies in you I swear, it ends" Lilly seemed to feel that they were emotionally separated and that she felt she had no desire for sex from her behalf. And she thought that her husband has coped with this through using his phone most of the time. It felt that she might thought this was putting her marriage in danger.

"if he holds his phone he enters another world, maybe I'm the only one who is not into mobile phones. Nowadays all men are addicted to mobile phones, young and old, they drive cars while having their phones in their hands."

When Lilly was talking about how her husband coped, she was normalising the use of phones precisely for men and probably comforting herself that there was nothing to worry about. She has specified addiction to using mobile phones only to men suggesting her perceived gender related differences. Lilly also asked me if my husband used his phone frequently, which perhaps indicates that Lilly was somehow concerned about what her husband might be doing and wanted a confirmation that what he was doing was normal and not concerning.

"Yes he does, how about your husband? Does he spend his time on phone?"

Theme 3: Healthcare experience:

Lilly's experience with healthcare support for prolapse is discussed under this theme. Lilly spoke about her feelings towards healthcare and perhaps the potential cause of her feelings. As she asked to be seen by a female physician, Lilly had to wait for some period of time, but her symptoms got worse while she was waiting. When Lilly was finally seen by the doctor, she was advised to have hysterectomy. It deemed hard for Lilly to share her concerns to unmarried healthcare professionals particularly if they were sensitive.

Lilly did not seek healthcare support when her symptoms started, even after speaking to her sister who confirmed that she had a "drop". Lilly said this was because she basically did not like hospitals, and it seemed that if it was not for the miscarriage, she might not have sought healthcare support at all.

"I don't like hospitals, nobody does, that's why I did not come when I first had it, but the miscarriage was good it discovered everything, it might be a blessing is disguise/ silver lining as they say"

She said that nobody liked hospitals, perhaps she meant that it is common for some people not to like hospitals and she was normalising her feelings. Indeed, Lilly had her own categorisation of people's feelings towards healthcare, either people who like or people who dislike hospital, and she was from the latter category.

"I am from the type who does not go. Even when I'm pregnant, I don't go until its time for labour."

Lilly indicated that she would not go to hospitals when she was pregnant until she entered stages of labour. This perhaps suggests that she might had high tolerance for pain or there might be some other issues for why she did not like hospitals. Lilly then indicated that all her eight deliveries were with male obstetrician.

"all my deliveries were with male doctors, when you are in pain you don't care if you are being seen by man or woman, but when I was seeing Dr, (A) I was a bit shy because I don't feel it's like delivering a baby, so he asks me to expose the area for him to check and I tell him refer me to female doctor"

The gender of the physician seemed to be an important issue to Lilly when she seeks healthcare support. She would delay going to the hospital when she was pregnant until it was time for labour. But Lilly also said that the gender of the physician did not matter at time of labour as she would be in lots of pain. It could be that she might have concluded from her childbirth experience that she would often be seen by a male physician, and she did not want to agree on that while she would be at a point where she could tolerate pain. Going to hospital when labour had started could mean that she would be in intolerable pain so she would not have time to think whether to agree or disagree.

Similar issue might also be there in terms of seeking support for prolapse, Lilly did not seek support early possibly because of concerns that she would be seen by a male physician which was concluded from her childbirth experiences, and when she sought support, she was originally seen by a male physician and asked to be referred to female physician as she felt shy. But the process of referral took a long time, and her access to the specialist doctor was delayed many times.

"he referred me to Dr, (I) whom I have waited for months and never seen, (Pause) moving from one appointment to another and she never comes or throws me to the residents list"

By saying "throw", it felt that Lilly might have thought that her problem was being underestimated by the doctor or that her problem was perceived less serious to be seen by a specialist doctor. Waiting to be seen by a specialist doctor for some time has made Lilly to feel that her symptoms got further worse.

"I was complaining a bit of heaviness but not like nowadays, the drop has increased, (Pause) first I had some pain but now its more and more"

Lilly felt she disadvantaged by her late access to the female specialist doctor given the progression of symptoms, she had the option to manage the condition with a male doctor, but she chose to be seen by the specialist female doctor; however, it felt that Lilly was blaming healthcare for the regression of her condition. Indeed, instead of talking about the symptoms she had as effect of prolapse, Lilly was speaking of them as a result of her late access to the specialist female doctor.

"At the end I have waited for some long period and the urine does not come out and I was having so much pain, when I'm sitting there is like a ball coming out of my uterus and the urine does not come out and this is torturing me"

Her prolapse increased and she started to feel that her urine is trapped because of it. This was associated with a lot of pain as Lilly used the word "torture" to describe the severity of pain. The effects of the regression were not only physical but there was also some level of psychological implication as Lilly said:

"I started to neglect myself, you start to have a mental state, you don't want to go out, you just neglect yourself and that's it" Lilly said she eventually ended up neglecting herself because of what she has been feeling. She said she was uncertain if self-neglect was common after prolapse or she was the only one feeling it. Lilly described what she was going through as a mental state, this seemed that it was something internal and personal that she perhaps wanted to deal with it alone, and perhaps she did not want to discuss it to anyone, even to her sisters who have been through the same experience which could explain her uncertainty of this mental state.

"I don't know whether it's with everybody or just me."

This felt like an important implication of prolapse to her as Lilly has mentioned this when she was introducing herself to me in the interview.

"I spend most of my time at home, I don't come and go anywhere"

But when Lilly wanted to speak in elaboration about how her symptoms have regressed so far, it was important to her to know my marital status first.

"I won't be able to explain if you are not married, I won't be comfortable speaking."

Lilly said that she would not feel comfortable speaking about sensitive issues if I was not married, and after telling her that I was she was able to open up. This perhaps is relevant her cultural perspective that is discussed under the last theme.

After being seen by a specialist female doctor, Lilly was advised to have hysterectomy and she has accepted to do the surgery.

"it's better to have it removed. I have been suffering for years now."

Lilly was perhaps aware that there were other surgical ways from her sister's experience, apart from hysterectomy, to manage prolapse. But this deemed the right option as removing the uterus might have meant that it was the end for her long suffering. Nevertheless, she was told that there were two possible outcomes for the surgery.

"The doctor told me that even if we did the surgery, we don't know whether the urine problem is still going to torture you or it may return

# sound, I mean it might return to its normal condition, I mean there are two probabilities."

Lilly was told that her urinary symptoms might or might not resolve after hysterectomy. She was told there was a possibility that her urinary symptoms would still be there after the surgery yet she decided to go ahead with it and said she was being optimistic with surgery outcomes.

Theme 4: Cultural and religious perspectives:

This theme represents Lilly's unique cultural and religious perspectives. Lilly shared her view on the lives of women, and the view women typically have about men and their roles. Gender segregation and the taboo of discussing sensitive topics also were emerging. Lilly's religious perspectives were also briefly evident in the transcript.

Culture and religion had inevitable impact on Lilly's overall experience. Her narratives were an indication of lives of women in her context. This was evident as Lilly spoke about the causes that made her and her sisters to have prolapse.

"You know, we women and the heavy lifting"

When Lilly first started talking about prolapse, she immediately stated that it was because she was a woman and was often involved in lifting heavy objects around the house, it felt that she was normalising this as part of her roles as a woman. Her discourse suggest that she perceived this to be a common act among women because she and her sisters perhaps were doing so. From Lilly's standpoint, pregnancy was also perhaps something expected from women. She did not say that she used to get pregnant under any external pressure, rather she was owning that responsibility of getting pregnant every two years. This perhaps could be attributed to the view of pregnancy in culture, and the potential value of large families in some societies in Saudi Arabia. Maybe Lilly had preference for large family, and this was perhaps influenced by her surrounding and culture.

Menopause is defined as the cessation of menstrual cycle. In some Saudi Arabian and Arab societies, "desperate age" is a common way of referring to menopause. When Lilly wondered about the reasons for why her period had stopped, she questioned whether it was because of prolapse or because she reached the desperate age.

"I don't know whether I have reached the age of menopause "desperate age" or it's because of the drop"

Calling it desperate age might mean she was no longer able to conceive, this perhaps reflects the way that she perceived she was viewed by society and the potential cultural view towards women in the Arab world about the roles of women in terms of childbearing. Given that Lilly chose to say "desperate age" it perhaps reflects her own view towards herself and other women after reaching the age of menopause.

Lilly also shared her views on men. To begin with, she thought that sex life affected men and did not share her view about women. But she could perhaps meant that she felt that sex was more important to her husband than to her as he was the man further reflecting Lilly's gender related ideologies.

"I know that marital relationship affects men yes, but what am I supposed to do?

But it felt that she did not think that it affected her husband much, her husband's patience was interpretated as weakness.

"I don't know but my husband is weak, (Pause) there are no weak men"

It sounded as if his behaviour was not masculine in her perception, and she might have expected different response. The cultural view towards men is that they are controlling and dominating as she said "there are no weak men" and it perhaps made Lilly to expect that she would see less understanding and more forceful response. This common view was further evident when Lilly said:

"The lady who was doing my urodynamics was asking me about my marital relationship as well, I told her it's all trash, she said believe me its not because of this thing you have, men are the reason" Lilly said she was asked about her sex life during urodynamics assessment probably by the nurse and she answered her by saying "it's all trash" and her metaphor suggests that she was extremely unhappy with her sex life. And the nurse on her behalf told her that the reason for her disturbed sex life was her husband not her prolapse and Lilly seemed to agree with her as she said:

"I told her yes you are right (Laugh), they always rain on your parade she made me laugh"

There seemed to be an image or perception of a strong man that Lilly perhaps thought that her husband was the opposite of it. Lilly mentioned a couple of times that her husband was understanding and supportive of her condition, and he allowed her to be seen by a male physician so she would not have to wait until she was seen by a female physician.

"my husband used to tell me to let him check instead of waiting for weeks or months to be referred so I let him check"

Maybe this was one of the factors together made Lilly to think of her husband as a week man, she was supporting gender segregation in healthcare particularly because she thought her problem was less serious than pregnancy.

Lilly's level of comfort while discussing sensitive issues to healthcare professionals was limited by their marital status. Lilly felt less comfortable to elaborate before knowing that I was married. It is possible that Lilly felt talking about her reproductive health to unmarried women, particularly young women who never had sex, was considered taboo and this was perhaps informed by her societal background.

Lilly's religious beliefs also emerged in her narratives. She has mentioned God in different context, for example when she was being thankful, she said:

"it was not malignant, praise to God"

What Lilly said was perhaps relevant to her perception of destiny, she knew that it could have been worse and the tumour she had could be malignant. But she was thankful to God that it was not, and perhaps thought that it was God's will for her to have a benign tumour. Her belief in God was also there when she was told about the potential outcomes of hysterectomy and the fact that her urinary symptoms might not resolve, but Lilly's response was:

#### "I have faith in god and I hope it goes well (Inshallah)"

It felt that Lilly was being optimistic through depending on God that things would end up well for her. Lilly said "inshallah" that means by God's will, she seemed relying on the will of God and hoping that she would get better. Furthermore, as she spoke about pregnancy and her children, Lilly followed her sentence with saying:

#### "may God protect them"

Lilly's dependence on God to provide protection and having optimistic view and faith could suggest that she felt she had no control as a human being and there was no element of chance of human intervention rather what was destined for her would happen anyway under the will of God.

#### Conclusion

Lilly shared the causes she thought have caused her to have prolapse and the level of control she had over these causes. Lifting heavy objects around the house, pregnancy, and early marriage was not entirely under her control rather it was informed by her context. Knowledge was also identified as theme as Lilly rationalised these factors as cause for prolapse and indicated she had some knowledge about prolapse risk factors but did not relate this knowledge to herself. Given that prolapse was a common problem in Lilly's family and the subsequent impact prolapse had on her roles within her family, Family was one of the main themes generated out of Lilly's transcript. Her experience with healthcare also deemed as a theme given that Lilly had attempted seeking professional healthcare support with the specialist doctor and has been delayed. Lilly further shared her cultural and religious perspectives that also informed her overall experience with the condition.

Lujain:

#### Generated themes

Theme 1: Understanding of prolapse:

This theme represents Lujain's understanding of prolapse. It discusses her reasoning for developing the condition and the ways it has affected her. The causes of prolapse that Lujain provided, which reflect her mindset and the way she made sense of her condition. This theme also considers the potential effects of prolapse on Lujain's life that shaped her personal response towards her illness.

Lujain felt that she developed prolapse mainly for two reasons: occasionally lifting heavy objects, and aging.

"I said maybe it is from lifting, sometimes I lift like a water gallon or push something heavy, maybe."

Lujain said she was living a comfortable life but thought that lifting heavy objects occasionally or pushing furniture has caused her to have prolapse. But she was not certain if it was relevant to cause her to have prolapse as she begin the sentence and ended it by saying "*maybe*".

Aging was also perceived as a leading factor to prolapse, Lujain has said:

"I also feel that it could be because of aging, you see an individual develops sagging and loose skin with aging, the tummy sags, the arms sags, so it is obvious that the uterus also loosens up and sags."

She provided a personal explanation of how advancing in age could affect the body including the uterus causing it to be loose and saggy, and by using the word *"obviously"* it felt that Lujain was certain that aging is a potential risk factor for prolapse. Her rationalisation of the condition suggests that she might have perceived that having prolapse at her age was inevitable which implied her resignation to the condition. She herself was 61 years old, and she might have thought that she was old enough to start having her perceived signs of aging.

However, Lujain chose to discuss aging as a factor in relation to women in general instead of reflecting on herself or indicating that she was growing old. It is possible that it was hard for Lujain to refer to herself and say that she was growing older, indeed, she has started introducing herself by saying that she looked younger than her actual age.

# "I look younger than my actual age because I am always pampering myself."

It seemed that Lujain was resisting signs of aging or looking relatively old by looking after herself. When linking aging to prolapse, she said that the body is expected to change with increasing in age, the arms and abdominal muscles would get weak and loose. Lujain has indicated that she has been doing exercises and some were focused on strengthening abdominal muscles. It felt that Lujain was trying to counteract the effects of aging and perhaps control the process through exercising.

"It just at the time of intercourse it becomes more and more, I mean it becomes more prominent. But throughout the day I don't feel it, see when I do any workout, abs workouts, I feel like it's going out and then back in when I tighten my abs."

Lujain said that prolapse has resulted vaginal protrusion that is often noticed during intercourse or when she did any exercises, particularly, abdominal exercises.

"During intercourse, it gets more prominent, it comes out more like this and it is red in colour"

The only symptom that Lujain reported to have was vaginal bulging that she said was not associated with pain or discomfort even during intercourse. And it was not constantly felt as she only felt it during certain activities. Hence, the only symptom Lujain has indicated to have did not seem to affect her greatly.

"It doesn't bother, it just goes in and out, in and out. (Pause) For an hour it is up and next hour it is down."

Lujain has said that she did not feel bothered by prolapse, perhaps it was not posing any personal difficulty to her. Given the current status of her prolapse, Lujain has indicated that she was fine with having prolapse and did not mind living with it.

## "I am fine I swear, I have no problem, I am fine with it even if I have to live with it."

It felt that Lujain was willing to cope with her condition as long as it was not bothering her. She has indeed repetitively mentioned that she was not bothered by it. Nevertheless, Lujain eventually sought healthcare support for reasons that were merely externally influenced.

### Theme 2: Family:

This theme demonstrates Lujain's roles within her family, and also her family's role within her overall experience with prolapse. It discusses how family has influenced Lujain's experiences in terms of building her knowledge about prolapse and shifting her personal response from willingness to live with the condition, to have concerns about her future with prolapse and deciding to control her problem and seek healthcare support.

Lujain's narratives suggest that she had few active roles within her family. Her children were grown up and she had a stay-in housemaid to do the housework.

"I mean I am happy and comfortable. (Pause) All my children are grown up, my daughter who's here with me is the second of my children. I have a son who is 40 years old now, and she is 38."

This perhaps reflects that Lujain had no parental responsibilities towards her children. Hence, having prolapse did not interfere with her role as a mother towards her children as it appeared that Lujain essentially was not required to provide care for her children at this point.

But Lujain seemed to have one active role within her family, and that role was being a wife. She has not indicated if there were certain duties or obligations she had towards her husband, but they had an active sex life. Hence, Lujain felt that the vaginal bulging resulting from prolapse has been interfering with her intimate relationship with her husband. Her husband has told her that he was bothered by the prolapse during sex.

"I am telling you he lifts and penetrate from underneath, that's the only issue (Pause) that he is bothered (Pause) He told me that he is bothered a bit but he said he has no problem with it, otherwise there is frequent intercourse."

Lujain felt that her husband was bothered by the unease of intercourse that was resulted from prolapse. But he also told her that he had no problem with it and maintained active sex life through finding a way that Lujain felt it has made it easier for himself. It felt that his response towards her condition was influenced by her response towards her own condition, she indicated that she was not bothered by her condition, and she felt her husband did not have any problem with it apart from being bothered by some difficulty during sex. Yet, despite his response and him comforting her and telling her it was not a big deal for him, Lujain still perceived this to be an "issue". She seemed to be very passive in her response to it and in her acceptance of her husband's response

When Lujain started to notice the vaginal bulging, she began by sharing her condition with her mother. She had willingness to share the burden of the condition with those closest to her. Indeed, Lujain's mother seemed very close to her as she has indicated that she often visited her during her free time. Her mother informed her that her sisters were having similar issues.

"I was worried I didn't know what it might be. Then I called my mother and told her about it and she said that even my sisters have the same problem. (Pause). But mine is not as serious as theirs."

Lujain's mother shared the experiences of her sisters with her in some great details. Indeed, it seemed that this has become a source of information for Lujain about prolapse in general. Lujain has indicated that she had no previous knowledge about her condition, and after speaking to her mother and the details she has shared with her, it appeared that Lujain's knowledge about prolapse was built through comparing her condition to her sisters. To point out, the information she had were given by her mother and Lujain did not speak to her sisters even after knowing that they had similar problems and Lujain did provide reasons for why she had not spoken to her sisters. It is possible that this was because they did not share their experience with her directly either.

"I don't feel anything else unlike my sisters. They haven't done any operations or anything. (Pause) I mean my older sisters, the eldest has her uterus really descending, the other one I mean is less than the 1st one but more than mine"

Through constantly comparing her condition to her sisters, Lujain might have understood that it is possible for her condition to get worse over a period of time. She started to have future related concerns about how prolapse would progress over time affecting her ability to control urine.

"But they say if I leave it as it is for a while (Pause) for 5 years 10 years, it goes down more, but I don't know. (Pause), so then it goes down even you cannot control your urine, that's why I got scared"

As her knowledge about prolapse was developed through reflecting on her sisters, it felt that Lujain was viewing her own experience through the lens of her sisters' experiences. She seemed immersed in what would happen to her next and concerned about controlling the progression of prolapse symptoms, while paying little attention to the symptoms she actually had.

"I mean even now I am telling you sometimes when I use the toilet and then wash (Pause), I push my fingers in like this I feel like something is trapped in and then a bit of urine comes out, this is how I feel."

Her discourse suggests that she already had urinary problems, but she did not speak of it in a context of being an actual problem that was bothering to her rather she was worried that she would end up having urinary incontinence. And she said she decided to seek healthcare support before she starts having those issues.

Theme 3: Seeking healthcare support:

The third theme generated from Lujain's transcript represents the reason she has provided for deciding to seek healthcare support, that was controlling the progression of symptoms and developing urinary incontinence. And it also includes Lujain's response towards having hysterectomy as a way of managing her condition.

Lujain was speaking openly about her experience, but when she moved on to discuss issues related to sex, Lujain asked about my marital status:

Lujain: During intercourse I mean even (Pause) Are you a girl yet or you're married?

FA: I am married, but why you're asking?

Lujain: So I can talk in details (Laugh), I mean even during intercourse I am telling you he is bothered.

It was felt that Lujain would not have spoken about her sensitive issues if I was not married, this is further explored later on.

It can be assumed that Lujain might have coped with her condition but decided to seek healthcare support after listening to the stories of her sisters through her mother. Hence, she wanted to avoid the progression of the symptoms in the future.

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"I said to do the operation before these other problems come, that's why."
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It seems that Lujain did not wish for time to control her condition and she wanted to be the one in control instead. This was perhaps similar to her response towards aging, she felt that over a period of time, growing older would adversely affect her body, health, and the way she looked, she took control to prevent this happening by pampering herself and doing exercise. Therefore, Lujain has been exercising to slow the time for herself, although it might be rare for women to obtain an active lifestyle in her context.

Lujain has decided to have hysterectomy to avoid having urinary incontinence in the future.

"But it's better for me to remove it, because if I lift it, it might go down again, so it is better to remove the uterus she said so you are in ease/rest afterwards."

A hysterectomy was advised by her doctor, and Lujain accepted the advice and deemed it suitable to her as it would put an end to her future related fears through controlling the problem regression.

"It's fine with me. (Pause) There is no problem (Pause)."

Lujain said she spoke to her husband about having hysterectomy, he agreed for her to have the procedure while saying that she was not in need for her uterus as she passed the age of conception.

"I mean if it is going to cause you as what I say any problems after a period of time then there is no need for it, remove your uterus, essentially you no longer conceive and so, I mean my period has stopped 4 or 5 years ago"

When she spoke to him about having hysterectomy, it was not clear if she was informing him about her decision or taking his approval for undergoing the procedure. And perhaps their responses would be different if Lujain was in a childbearing age. Lujain's husband might have also said this in a context of being comforting to her; nevertheless, this reflects many cultural issues that are explored under the following theme.

Theme 4: Cultural and religious perspectives:

This theme represents Lujain's unique cultural and religious perspectives. The role of culture in shaping Lujain's experience was evident when she narrated her sister's experiences with prolapse and the hidden concerns she started to have. Lujain has discussed the dominant role men acquire in marital relationship and it was reflective of the submissive role women would often obtain.

As Lujain was speaking about her sister's experience with prolapse, her discourse was suggesting certain gender specific roles and expectations that seemed to be informed by her cultural background. Lujain has indicated that both of her older sisters have not sought healthcare support for their problems. Her eldest sister was greatly affected by prolapse and that she and her husband were sleeping apart, Lujain saw this as a reason why she did not seek support.

"She complains of it and says it is really making her sick, but she her husband never even comes to her, I mean she is married and everything but they sleep in separate rooms, so it doesn't make any difference to her."

Lujain was saying that her sister did not sleep with her husband, and she perhaps meant that her sister did not have an active sex life and that it was not important to her seek healthcare support despite being really ill. It can be assumed that seeking healthcare support was important to Lujain because she had an active sex life. She said that her trigger to seek help was to avoid having urinary incontinence, but the actual trigger seems to be her sex life. But this was perhaps more about her husband than about herself. When speaking about her sister, Lujain said that *"her husband never even comes to her"*. And when speaking about her experience, Lujain said that her husband being bothered during intercourse was problematic to her despite that he comforted her many times by saying that it was not problematic to him.

"I don't know, I mean I feel you know how men are unlike us, they want everything to be easy, not lifting then penetrating"

This might be reflective of the dominant position men socially acquire in a marital relationship, and the subsequent submissive role women obtain. Indeed, Lujain seemed to believe that the ability to cope with challenging circumstances was also determined by gender.

# "I mean we are fine with things, we cope, and they get bored that it is not easy."

She was somehow concerned that her husband would have had enough with being bothered during sex. Her belief also suggested that she might be bothered but, for being a woman, she coped with her condition. The assumption Lujain had was possibly based on what she has seen in her sisters that demonstrate some culturally embedded issues. Lujain was the youngest of her sisters and the stories of her older sisters with prolapse, as discussed above, have influenced her own experience. Her eldest sister was coping with the debilitating symptoms of prolapse because her husband was not sleeping with her, and her second sister has also coped but for different reasons.

"her husband doesn't like to take her or bring her anywhere, thanks to god my husband I mean has provided me with means of comfort, he brought me a maid, (Pause) he is blissing me I mean"

Lujain saw that she has been privileged that her husband has provided her with means of comfort that made her life easy. She thought that her sister's husband responsibility as a man was to provide her with a housemaid and take her sister to seek healthcare support when she felt sick. Respectively, her sister as a woman had to cope and live with the resources that her husband had provided her with and self-manage her health problems.

"That poor she started to use medications and use mercurochrome until the wound was about to become rotten/ infected"

But the issue here seems that it was not the act of taking her to hospital, but her husband perhaps did not approve or gave her his consent to seek help. Acquiring a superior position might mean that the approval of men is necessary in terms of healthcare related decisions and giving agency to women in their families. Lujain's husband had comforted her by giving her agency to choose what to do with her body.

"I mean even this what is coming out of me he did not complain, he said yes it bothers me but it's up to you, it's fine with me I have no problem with it, it bothers me but it's fine. (Pause) He has given me freedom to choose what is more comfortable to me"

But this perhaps was contrary to her cultural beliefs as despite comforting her and telling her he did not mind, Lujain was still concerned that he would get bored because of difficulty in intercourse possibly because her perspective that men are dominant to women. Despite having detailed information about her sisters' condition, Lujain did not seem to approach her sisters to further discuss her problems with them. It is possible that discussing sensitive topics was taboo to Lujain, her mother told her about her sisters problems but Lujain might have not spoken to her mother about the implication of prolapse on her sex life. This was assumed because even when Lujain was speaking to me about how prolapse was bothering her husband during sex, she wanted to confirm that I was married so she could talk.

Lujain's religious beliefs were occasionally present during the interview. She was thanking God when she was talking about how good she thought her husband was.

## "thanks to god he is really good to me, if he sees anything in me, he tells me to go to the hospital"

This was said when Lujain was talking about her sister's husband and that how her husband was different than her sister's husband but in a positive way. She was perhaps grateful because she could have been in her sister's shoes and have a husband who would not approve her going to the hospital, or she could even have worse symptoms.

"It doesn't hurt me praise to god"

#### Conclusion

Lujain had her own understanding of prolapse in terms of causes and effects. Prolapse resulted in vaginal bulging, but this did not pose significant impact on Lujain as she indicated many times that she was not bothered by it and was willing to cope with it. But her own response towards her illness changed following speaking to her mother who told her that her sisters were having similar problem and knowing that it could get worse within few years. Lujain sought healthcare support attempting to control the progression of symptoms and decided to have hysterectomy. But Lujain's narratives reflected her cultural and religious perspectives that were indirectly affecting her overall experience and the decisions she made. Her experience was visualised as a top up hierarchical shape, the top would be Lujain's understanding while her cultural perspectives would lie in the bottom forming the base of the hierarchy. In the middle there would be family and how it influenced her experience, and her healthcare experience. The deeper Lujain's experience was analysed, the more it was reflective of her cultural beliefs.

Mai:

Generated themes

Theme 1: Understanding of prolapse:

This theme discusses Mai's understanding of prolapse. It represents her perceived causes for why she had the condition and the effect it had on her. It also shows her perception of prolapse as something possibly reversable.

Mai seemed to understand that she had prolapse merely for one personal reason. She suggested that her quick responses might have caused her to have prolapse.

"They would traditionally call it (Hata'a) meaning the descent of uterus, so they always tell me walk slowly, my problem is, even when once Dr, (I) saw me, she had my baby delivered last time, she told me don't move even during labour don't move, just stay "relax", I am really fidgety and quick do understand? Maybe this has a role in it."

Mai said she was told many times to take things slow. She has provided another name for prolapse and indicated that this is how prolapse is traditionally called. By saying "they", it felt that Mai was referring to people from her society. This could demonstrate that prolapse is a known condition affecting women in Mai's social context. She also mentioned that during one of her labours, her doctor told her to relax and not to move. Perhaps she felt her nature as a quick and fidgety woman might be relevant to her current problem because she has been advised to be slow.

Pain was the only symptom that Mai thought was linked to prolapse. She indicated that she felt pain occasionally when she made some effort around the house.

"I feels its descending especially when I move make an effort at home or push something, immediately I feel pain down there"

Mai said that doing housework cause her pain and she feels her uterus descending. It appears that pain increases her awareness of prolapse. It felt that Mai equated pain to the prolapse or maybe the prolapse was there, but she would only feel pain if she did any work.

The first time Mai felt her uterus descend was when she was lifting her husband because he had a health problem affecting his leg. She did not speak about this as a cause rather it felt that she was narrating the incident when it happened first.

"first my husband was very sick and I was lifting him, because of his leg and so, and I was lifting him and suddenly I felt my uterus coming down"

It is unclear how Mai identified the feeling that she had was her uterus falling down. Mai's given narrative reflects several issues such as her relationship with her husband and some cultural perspectives, both are discussed separately below. It also reflects Mai's perception of prolapse. She felt that her uterus came down suddenly but also said that she could lift it up again with some techniques:

"I don't feel comfortable unless I am lying on bed and lift it up with my hand, or I let a masseuse lift it."

Mai thought she was able to relieve her symptoms of pain and discomfort through reversing her prolapsed uterus and lifting it up back to its place. Hence, the effect that Mai perceived to be relevant to prolapse might not be greatly disturbing her and perhaps did not trigger her to seek support. Mai had two more symptoms that were relevant to prolapse, but she perceived them to be separate problems.

Theme 2: Urinary incontinence and voiding:

Mai was complaining of urinary symptoms. This theme demonstrates Mai's understanding of her symptoms, she had urinary incontinence and voiding but she did not understand what was happening and why it was happening. It further discusses the impact of the symptoms on her and her response towards it.

When Mai was asked to talk about her experience, she discussed the impact of the urinary symptoms. Mai felt that she was unable to control her bladder when she laughed or coughed which had an implication on the time she spent with her children.

"at first when I was at home sitting with my kids or anything, with any cough or laugh I tell them oh stop talking I will pee! And I cannot hold it and I pee, pee pee not small amount of pee like few drops or so, no!"

Mai has mentioned similar incidents of sudden urge to urinate when she laughed with her children and indicated that it has been really tiring and disturbing to her. The urinary symptoms she had also affected her in terms of praying and engaging with the society.

"Affecting me is when I pray, when I am out I feel I have to change my clothes, for example when I am somewhere out on an occasion I can't hold myself I have to go to toilet every minute, every while I empty the bladder and that's it."

What Mai said perhaps reflects some level of being self-conscious. She indicated that her urinary symptoms affected her when she prayed, and she used the toilet a lot when she was at social gatherings. She wanted to ensure that her bladder was empty so she did not have any urinary leaks as a result of activities that would increase her intraabdominal pressure such as laughing or coughing. Mai said she was "tensed by the urine story", and she perhaps meant she was bothered by her urinary symptoms.

Praying in Islamic religion requires a set of cleaning rituals, if Mai leaked urine, she would have to repeat those rituals again. Attending social gatherings might mean that Mai would be surrounded by her family and friends and being noticed to use the toilet frequently or leaking urine might be embarrassing to her. The sense of embarrassment was first noted when Mai was talking about an incident when she told the driver to stop by a mosque, so she used the toilet there.

"it was enough what already happened to me on the way, I didn't want the driver to understand I told him stop stop I want to pray because I was really in urge"

Mai told the driver to stop she could pray but she wanted to use the toilet. She seemed embarrassed. Mai did not speak about the reasons for which she thought she had her urinary symptoms, but it seemed to greatly affect her, and she was disturbed by its multiple implications. But Mai thought that it happened to her under the will of God, which might mean that it was her perceived cause for it or that she was accepting it as her destiny and being patient.

"what shall I do with my life aside from that it is Gods willing"

Mai began by saying that she had urinary symptoms but seemed uncertain of the causes.

"I cannot hold it, I am not in urge, I don't feel I am in urge to pee! But when I laugh I feel the urge, I don't know before, I was fine when I was having the urge"

Laughing made Mai feel the urge to urinate. It felt that Mai knew well about the implication of the symptoms but was narrating her experience with the urinary symptoms and how it has affected her. In addition to the physical impact, Mai seemed to be overwhelmed by her urinary symptoms.

"so I used the toilet 7 times within an hour! Every minute! I mean I used the toilet 6 times at the hospital so when I am on my way it should be OK I mean I don't have any"

#### Mai further added:

"So I went to the toilet again and I was done and was going out of the hospital, and just after 5 or 10 minutes I felt I was about to pee again!"

She said she would use the toilet frequently to avoid having sudden urge while laughing or coughing, but she was unable to empty her bladder and would feel the urge to urinate again because there would be urine residuals in her bladder. It was not evident if Mai understood this, but she seemed to be greatly disturbed by her urinary symptoms.

"I told her yes I have but I felt that's it I can push more, because I was trying to but there was no use, but in few minutes, I went to empty it, so 3 or 4 times there" To begin with, to avoid the sudden urge to urinate or leaking with laughing or coughing, Mai has limited her water intake.

"I want to drink beverages this is my nature I love drinking water but now I hated it because of using the toilet a lot, I am limiting it. See now I was out I did not drink but a small sip to avoid urging on my way"

UI appears to be the first symptoms Mai complained of and sought support to manage it. Her self-management strategy for it seemed to be working well for her because Mai indicated that she was greatly disturbed by it, yet she said she forgot to seek support again after delivery:

## "I said that's it, God willing after delivery I am coming, and I forgot about it"

It could be that Mai felt seeking support was unnecessary as after limiting water intake, she perhaps felt less bothered by her urinary symptoms.

Theme 3: Being wide:

Mai spoke about another major issue to her, being wide. As she thought that all her problems were distinct from each other, she thought being wide was a result of different causes. This theme discusses the causes she gave for herself being wide and the impact it had on her that was clearly related to her sex life.

Mai's third complaint was the sense of being wide which, in her perception, was mainly a result of episiotomy. By saying wide, Mai perhaps meant loose vagina. Mai had been pregnant eight times and had all her children through vaginal delivery and had had an episiotomy in each delivery.

"In all my labours they cut me from down there, and this is why I feel wide, the doctor tightened me up after delivery, but it was just external tightening which is different than the internal"

It felt that Mai had her own understanding of how episiotomy is done which justifies why she related episiotomy to herself being wide, Mai thought that there has been a cut to ease labour and the following incisions were only done externally. Moreover, Mai thought that pregnancy and vaginal delivery increased her chances of being wide.

"Especially with pregnancies and deliveries they play a role in this"

Mai's narratives in terms of being wide implied that she had disturbed sexual body image that affected her sex life.

"I feel myself really wide, uncomfortable and unhappy. I mean it is extremely wide!"

This issue was possibly of greater importance to Mai as it was a problem she shared with her husband, unlike prolapse and her urinary symptoms that Mai deemed personal to herself, despite the latter affecting her time with her children.

"the urine problem is really affecting me the most but also this issue is also affecting me and marital life"

The issue also appeared to have a direct implication of Mai's sex life as she has indicated that she felt unhappy with sex, this might be related to feelings that she was perhaps unable to feel anything during sex.

"you feel you are unhappy with this thing "intercourse"; I mean it is so regular, you understand, the world down there is really wide!"

Mai moved to speak about her attempts to manage her issue of being wide. She tried many things to manage her sense of being wide and the impact it had on her sex life. The majority of the self-management approaches she used were natural remedies, yet she felt the effect was not long lasting.

"although there are some natural things, I have tried but I feel its effect is temporary, at the same moment and that's all, you get me?"

## Mai further said:

"There is a gel sold at the pharmacy, but it only lasts for a moment, and there is also, oh I forgot the name of the gel, and they also told me about the use of pomegranate dried peel and salt." Her discourse suggests that she was willing to try things that were perhaps painful hoping that it would eventually resolve her issue and might make her feel tight again, but nothing seemed to work well for her.

#### "I mean I have tried like 100 things."

Mai indicated that when her sister shared her experience with her, she told her that she felt that her vagina was tighter after she had vaginal reconstruction. Mai said she responded calmly to her and apparently, she did not tell her sister that she was essentially feeling wide.

"but she says that the area get very very tight I told her that good let him be happy, but I am too shy to talk about this to anyone"

This basically seems to be what triggered Mai to seek professional support after three years. Prolapse itself and the urinary symptoms were manageable, but her attempts to manage her issue of feeling wide vaginally were failing and the last thing left to do was to have the surgery. To point out, Mai spoke quite a lot about the urinary symptoms, but she did not appear to feel that it was bad enough to need to be addressed. The wideness is though, this was related to her husband's feelings, her ideas about sex and her worry about him seeking it elsewhere. All these things then perhaps became more important than her urinary symptoms

### Theme 4: Family:

This theme shows the position of family in Mai's experience. It discusses how her overall experience has impacted her family and how her family impacted her experience. Mai spoke about the responses of her sister and husband when they saw her experiencing the symptoms and how she felt about it.

Mai said that one of her sisters had prolapse many years ago that has been managed through vaginal reconstruction. Mai said that her sister seen her using the toilet frequently and shared her past experience with her.

"she told me I wasn't like you, she said with every prayer I used to go to the toilet maybe once but you are going three times. You are going and going I told her maybe because I drank a lot of water, she said

## even if you did you should be able to hold it, I can hold it but I am concerned that if I cough I pee in the holy mosque"

Mai said her sister told her that her condition was different in terms of the frequency of using the toilet and ability to control the bladder. Mai indicated that she was using the toilet frequently as she was concerned of leaking urine if she coughed, and this was not related to her ability of controlling her bladder as her sister was saying but perhaps was a result of her inability to empty her bladder fully. And the concern was perhaps greater to Mai as she was at the holy mosque which requires her cleanliness if she was at the premises.

When Mai spoke about her sister's response towards her frequent toilet use, she did not indicate whether she shared her own experience with her in the first place rather she possibly viewed it as an intrusion. But later on, Mai said that she occasionally asked her sisters for advice and discussed potential solutions but indicated she would not share detailed information with them because she thought that it was a personal matter.

"I often talk to my sisters what should I do and so, but even my sisters I don't tell them all, maybe there is only one sister who I tell her everything otherwise no I am really embarrassed to say these things to anybody its private."

The sister that Mai was talking about her here was not the one who shared her experience with as Mai said:

"My sister has done this operation about 10 years ago, she is old. But she had the problem, I was too embarrassed to tell her that I have this and that"

It might seemed difficult for Mai to share her personal experiential concerns with her possibly because of age difference as Mai indicated that she was 'old', and it also could be because of her response towards her condition that seemed lacking compassion. Nevertheless, Mai was often comparing her condition to her sister's. And she noted that her sister was using the toilet less often and Mai thought that this was because her condition has been surgically managed. "we go to the holy mosque I use the toilet maybe 6 times and she hold it from afternoon till the evening, I can't impossible for me, she might be better because of the operation"

It felt that her sister's experience somehow shaped her own understanding of what would be expected from healthcare and that her condition would get better after she has the surgery.

Mai narrated her husband's response about her condition. Apparently, her husband did not share his response towards the other symptoms she was having except for being wide.

## "he told me you are really wide why don't you tighten yourself or do something about it?"

Mai indicated that she felt that the issue of being wide affected her marital life, and this was evident indeed when she spoke about how her husband reacted about it. She was personally unhappy with her sex life and felt neither he was, which might have increased the burden on Mai.

"And even he is unhappy and feels it is too regular, to an extent that he would ask to do it from behind! Meaning you are really wide down there, and you have relief me by any other way."

Because she felt that her husband was unsatisfied with vaginal sex, he would ask her to have anal sex and it seemed that she accepted that, which perhaps meant that sex was important to her. The way Mai said this suggested that it was big deal for her because anal sex is prohibited in Islam, this is further discussed under the theme "cultural and religious perspectives".

Maintaining a happy sex life was important to Mai for personal reasons and reasons related to her husband. She personally thought that its importance is relevant to marital relationship.

"I mean this thing is really important it gives colour to your marital

life "

By saying this, Mai might mean that a happy marriage is an indication of a happy sex life, and she wanted her marriage to be stable and happy. Because she was unable to make him happy, Mai ended up having concerns about her marriage:

"I mean you bear in mind that he is unhappy! I was worried that he will go out or anything else"

By saying "he will go out" Mai perhaps meant that she was worried that her husband would have extramarital relationships or seek another wife to fulfil his sexual needs as she felt that he was unhappy and dissatisfied with their sex life. Mai then spoke about what sex was for her husband:

"He also had depression a while ago and I felt that the sex was extreme like crazy, and I hated it sometimes, do depressed men like sex? Have you heard about such thing?"

Mai thought that intercourse would be extreme at the times her husband was depressed. It was not clear what Mai meant by extreme, but it is possible that she thought that it was the only thing that took him out of depression. Hence, it was perhaps important for her to ensure that he would be at least sexually happy if he was ever depressed.

Family seemed to be very important to Mai. She rejected a job offer after being accepted for the sake of looking after her children and the duties she had at home.

"I am a teacher, I got job acceptance, but I never worked. I didn't want to because of the duties I have. I am busy with house and kids."

The urinary symptoms Mai had mainly seemed to affect her responsibilities towards her children, particularly the time she spent with them. Mai indicated that she was disturbed by the sudden urge to urinate or leaking when she laughed with her children.

*"if I am sitting with my children watching TV and comes a funny scene or they make me laugh I tell them don't make me laugh don't and I immediately use the toilet, I pee in fact, I can't tolerate it"* 

Mai's commitment to family also seemed to be one of the reasons that restricted her from seeking support. She mentioned that she sought support when she started to have urinary symptoms but was pregnant at that time, so she did not receive any management as she was planning to have vaginal reconstruction after having the baby, but she got pregnant again soon after.

"Essentially, the doctor told me an operation since 5 years, she said come after 6 months after delivery I was pregnant back then."

Mai perhaps felt that her condition required medical intervention, but she seemed to have no time to do so as she was busy looking after her children and maintaining her responsibilities towards them.

"I mean house and duties, every time I thought of going something came up, sometimes it was hospital issues and sometimes personal issues, I have a lot of duties at home with my kids and my daughter's wedding"

Mai indicated that she often visited private hospital but recently there has been a change in their financial status, so she started visiting governmental hospitals as they provide free medical services. She was financially dependent on her husband; hence, there was possibly limitation in the resources provided by him.

"All my deliveries were normal at (..) hospital but the last three I had them here at university hospital as there was change in budget."

Theme 5: Asking for vaginal reconstruction:

Mai's aim of seeking healthcare support is discussed under this theme. She basically sought the support to have vaginal reconstruction that was suggested for her many years ago. But she found difficulty disclosing private information to healthcare professional for confidentiality related concerns and the marital status of healthcare professionals involved with her.

Mai said she wanted to have vaginal reconstruction; her main reason was because she felt she was wide. She also indicated that she was asking for the surgery because she had prolapse. "I want the doctor to lift it up for me, I feel myself wide. Moreover, I feel that the uterus is down, so what is going to happen? Is the doctor going to lift it? I feel like this"

The questions Mai asked were reflecting that she did want to have surgery and wanted a confirmation. She also perhaps perceived herself eligible for the surgery because she had eight children and she thought that pregnancy, childbirth, and episiotomy caused her to have prolapse in the first place. Her request to have vaginal reconstruction appears to be because she felt that it would make her vagina tighter.

"And also, the story of the uterus I feel it is descending and I want her to tighten it for me I had 8 kids"

Surgery was essentially decided for Mai five years ago when she first sought support, but it was delayed as she was pregnant at that time.

"the doctor told me an operation since 5 years, she said come after 6 months after delivery I was pregnant back then"

Mai did not indicate what surgery was decided for her, but the decision was based on the doctor's assessment.

"I saw the doctor and she explain that I have to squeeze and lift the uterus, but she didn't see that it was working for me that's why she told me to do the operation"

Mai was asked to squeeze and lift her pelvic floor muscles, and perhaps by saying that the doctor did not see it was working for her, Mai meant that her muscles were too weak; therefore, surgery was deemed suitable by the doctor.

When Mai wanted to speak about the implication of being wide on her sex life, she asked about my marital status. Then she indicated that understanding her experience would only be facilitated if I was married.

"You feel unhappy, that's why I wanted to make sure you are married so you understand" It is possible that she often felt talking about sexuality related concerns would be difficult to be conceptualised by unmarried healthcare professionals. But during the interview Mai said couple of times that she was broadly shy speaking about her condition because she thought it was private and culturally sensitive, hence, speaking to a married HCP could reduce the potential stigma around talking about such sensitive issues.

Mai said she was seen once by a doctor who she found out she was related to. Mai shared some private information during the interview about herself and her relationship with her husband, but it felt that she was later concerned about her confidentiality as she said:

"I used to see a doctor here and we found out we are related"

Theme 6: Agency in personal choices:

This theme represents the level of control Mai had over her personal life choices, particularly pregnancy. Mai spoke the control of her family: close and wide in her life and also about the control of God, but she had limited personal autonomy.

Mai said that she wanted to have surgery because she had eight children. Her personal control over the choices of pregnancy was not evident as her family's control. Mai basically said that she had three daughters and a one son, and she decided to get pregnant because her son wanted a brother.

"my son wanted a brother and I said ok lets have a son, my mother in law, my father in law died, when I was in labour she asked me what am I going to name him, I said I vowed to name him after the prophet Muhammed, she said why don't you name him after your father in law? I told her I have already vowed, my husband told her ok the one after him, I said no that's enough, and he sworn next year, and next year I was pregnant"

What Mai said perhaps reflects that her family: close and wide, was involved in her pregnancy related decision. The first pregnancy was to make her son happy, and the second one was under the control of her husband perhaps to please her in laws who wanted to name her son after her deceased father-in-law.

Mai got pregnant one more time soon after, but this time she wanted to have an abortion. But when she went to the hospital, they asked for her husband's approval.

"I went to her and told her I want to abort him, she said if your husband agrees bring me a signed paper that you two want to abort the baby, I told her ok"

Mai appeared to simply accept what the doctor said possibly because this was informed by culture and that women often do not go under any surgical procedure unless the consent was signed by male guardian. But when Mai was filling the form, she received a call from her sister-in-law who was apparently not happy with Mai's decision.

"my sister in law called me told me shame on you I have two sisters one did not have a child ever and wishes for one even if it was a cat, and the other one has a boy and a girl and wish to have one more, and you want to abort him! This is our son bring him we want him, she wanted to adopt him and I was intending for it"

Mai said that her sister-in-law responded to Mai's decision of aborting the baby and told her that she was willing adopt while indicating that he was their son. Mai was willing to give her the child for adoption and did not seem disturbed by the way her sister-in-law spoke to her or her intrusion in her personal decision. Mai said she was going to do the abortion procedure with a doctor who was a family friend, and this was perhaps how her sister in law knew about her decision.

Mai's narratives broadly suggested that she had no personal autonomy in terms of family planning choices. She said she tried using one contraceptive method that she thought did not work because of prolapse.

"I had intrauterine device for contraception placed in me, I used to feel (Pause) even when the doctor came to remove it, she said it is already out meaning the uterus is really really descending" Mai's narrative was partially missing here, she did not indicate what was she used to feel or whether the intrauterine device fell out of her or maybe she felt unwell because of it. But it did not seem that she considered using any other form of contraception. But she has further confirmed that pregnancy was not under her control, which perhaps suggests that she did not use any or was not convinced to do so.

"so its abnormal to hear oh you still get pregnant, it is not under my control what should I do! If it was in anyone's control, then those who wanted children would have them!"

Mai said that people's response to her pregnancies was perceived as abnormal to her. She believed that pregnancy was not under the control of anyone but God; hence, she sounded distressed when saying this. Yet despite her belief of pregnancy being under the control of God, Mai considered abortion in her last two pregnancies.

"I was 46 back then I mean I no longer wanted but god wanted me to be pregnant, so I did not want to abort him."

Nevertheless, this suggests that Mai felt lack of autonomy, she believed that God would decide for her particularly when it comes to family planning, and at times it felt that it was informed by her family. Yet Mai thought that such decisions were basically under the control of God. She said above that God wanted her to get pregnant despite her not wanting to and husband promised his mother that he would have another son to call him after his father.

Pregnancy was also deemed under the control of God when Mai spoke about how she got pregnant with her last child:

"so I prayed for her from the deep of my heart, next month she called me telling me she was pregnant, and so was I. They say when you pray for someone the angels will pray the same for you"

She did not perceive it as a possible result of having unprotected sex rather she linked to her religious beliefs. And even when she wanted to abort the baby, her perception that she got pregnant under god's will made her to step back from her decision and keep the baby instead of aborting him or giving him to her sister-in-law.

"then I changed my mind I said this is god's given and gods will, and it was the "for you the same" that stopped me otherwise I was giving him away."

#### Theme 7: Cultural and religious perspectives:

Mai's cultural and religious perspectives are discussed under this theme. The impact of her culture was evident multiple times during the interview. And in terms of religion, Mai mentioned God many times, so it reflected that she was a religious woman. But Mai also contradicted some religious roles so there was an apparent conflict between her religious beliefs and the impact of her symptoms on her.

Mai's overall experience with prolapse and subsequent symptoms reflected certain cultural and religious issues. When she spoke about her close and wide family, and the involvement of her in laws in her personal decisions, it demonstrated the family dynamics that are common in Saudi Arabia. To begin with, Mai said that she rejected a job offer as she had to maintain her responsibilities towards her close family. It felt that she had to compromise her career because she was a woman, and perhaps it was not important to her to work as her husband was. This could be rooted in the cultural traditions in Saudi Arabia that women are ought to stay home and look after family, while men are expected to have a stable job and provide family with resources. Respectively, women are usually? financially dependent on men. Indeed, Mai indicated that she had to seek support at governmental hospitals because there has been a change in their financial status because her husband bought a new house.

Being dependant on her husband financially might have made Mai feel subordinate in the relationship, this perhaps was acceptable to Mai as it was culturally common. She appeared to be living with the available resources without being demanding, indeed, Mai said that their car was high and getting into and out of the car made her feel pain in her uterus, but it did not seem that she has spoken to her husband about it. Moreover, her husband also pointed out to her that she was "wide", and she was not saddened by the way he said it rather she was concerned about him that he was not sexually happy or satisfied.

Mai spoke about her in laws few times during the interview: when her mother-inlaw asked her to name her child after her deceased father-in-law, and when her sister-in-law called her to tell her not to have abortion. It felt that her in-laws also acquired a superior position in her life and she did not seem to mind. It could be that because this was something culturally common, the husband's family sometimes are granted power over the wife's choices more than her own family.

Mai said that she did not like to share her private information or talk about the implication of prolapse or being wide on her sex life. And when she wanted to talk in detail during the interview, she asked about my marital status. This possibly is because of the sensitive nature of her problem but also because talking about such issues is culturally taboo and it is not often discussed. Mai said that asking about my marital status was important for her to ensure that she was being understood. This further asserts that because these issues are not discussed with unmarried women, Mai thought that I would understand her concerns as I was married.

Religion also emerged from Mai's narrative, particularly when she spoke about agency. She believed that her pregnancy was under the will of God. This perspective is relevant to the concept of destiny in Islam which implies whatever happens to one was already written for them before they were born. Even when Mai was talking about the effects of her urinary symptoms, she seemed to believe that it was God's will, and she was destined to have this.

Mai said that her last pregnancy was because she prayed for her friend to get pregnant at the holy mosque. What Mai said was something religiously well known that praying for someone would make the angel pray the same thing for the one who prayed. Hence, Mai thought that she got pregnant for religious reasons.

But at times if felt that Mai was contradicting the common religious roles despite her narratives that demonstrated that she was a religious woman. Abortion is prohibited in Islam and it is often not practised at authorised hospitals, but Mai considered having the abortion undertaken by a doctor who was a family friend. Mai also spoke about another religiously prohibited issue when she was talking about her husband's response towards her feeling vaginally wide. Mai said that her husband would ask her to have anal sex, and she sounded surprised when saying that. Mai perhaps was aware that this is something religiously unacceptable, indeed, it has been said in the religious texts that couples who have anal sex are cursed by God. Yet, her husband asked her for it as he was unpleased with vaginal sex, and it seemed that she was accepting it as she perhaps had no other option.

### Conclusion

Seven themes were generated out of Mai's transcript. What was unique about Mai was that she thought that the different symptoms she was experiencing to be distinct to each other while believing that she had three separate problems. Family played a critical role in shaping Mai's experience including her response and healthcare seeking behaviour. The impact of Mai's personal beliefs informed by culture and religion was evident throughout the interview.

Nabeela:

Generated themes

Theme 1: Understanding of prolapse:

This theme represents Nabeela's understanding of prolapse. It demonstrates her reasons for why she thought she had prolapse and also discusses the effects it had on her. Nabeela provided a few reasons as to why she thought she had a prolapse. She first said that the condition was a hereditary, she felt it runs in her family.

"This is a hereditary condition, my grandmother, my mother's mother had a descending uterus, and my mother uterus also descended"

Her grandmother had it, and her mother also had it; respectively, Nabeela made sense of it as a condition that possibly all women in her family had it or eventually would have it. This seemed to be a generic explanation for having prolapse, but Nabeela then narrated a personal event and indicated that it was a potential reason for her to have the condition. "I had about two years ago, and before that I swear there was nothing wrong with me. It was Eid holiday and maybe I carried a lot of stuff and put them in a bag, and I got tired from carrying and putting, glory to God, maybe this is why I had it. That day I remember I made an effort and then I went to the washroom, and I was bleeding. Praise God, maybe it was written for me in my destiny to have this that I got tired and tired, and when I collected all the stuff at home and put them all together in bags and carried them, there were a lot of bags maybe 5 or 6 bags."

Nabeela said she noticed that she was bleeding after lifting heavy bags around the house during the holidays, and further said that it might be the reason why she had a prolapse, because she felt she made quite an effort that day. But Nabeela also said that she might be destined to have prolapse. Her discourse suggests that she felt that she had no control over developing prolapse, and there seemed to be some level of acceptance. It is possible that Nabeela thought that having prolapse was inevitable given her reasoning for it as a hereditary condition and her faith in God.

Nabeela spoke about the impacts of prolapse. She felt that she was unable to urinate easily because she thought her uterus was all out and was blocking the urine passage. She also mentioned some other issues such as pain and inability to sit on the floor.

"I feel a descent in my uterus its descending, descending, imagine it even blocks the urine passage!! And now I even can't sit on the floor! It's very descending extremely descending! I can even hold it between my fingers, like if its hanged a bit and descending, and there also comes tummy ache and back pain and pain on my knees and they told me that's because of roughness in my knees"

She had other health conditions that appeared to be sometimes overlapping with prolapse symptoms, she indicated that she had abdominal pain, back pain, and knee pain in the context of how prolapse was affecting her. But later on, mentioned that the knee pain was relevant to knee osteoarthritis. Osteoarthritis is defined as the degeneration of any given joint's bone and cartilage, but in Arabic language it is commonly known as joint roughness. Nevertheless, overlapping of symptoms was also sensed as Nabeela spoke about her inability to sit on the floor, she said:

"Yes I sit a lot on the floor but as I am telling you I can no longer bend my knee and my uterus bothers me and makes me tired and ill"

It was unclear whether she meant that she was unable to sit on the floor because of her knee pain or because of prolapse; hence, there seemed a bit of confusion, indeed, Nabeela was also mixing up her hospital appointments during the interview and the first time when her condition started.

"Oh no you're right I have it since a year and half, in Hajj holiday not last year but the year before."

Nevertheless, Nabeela's narratives reflect her perception and rationalisations of prolapse. She was repetitively saying that it was "extremely descending" and was providing verbal illustration of prolapse by saying that she felt as if it was "hanged". Perhaps she perceived her condition to be very severe, and it felt that Nabeela seemed to think that nothing would be helpful in managing her symptoms conservatively. When she was asked about what she has done so far to manage the pain and bothersome sensation, she said:

"What can I do? Like what? Exercise? What can I do? It's very descending its blocking the urine passage. Its descending but I feel like if it's hanged"

she further said:

"even when I wipe with tissue I find blood sometimes. Blood because the meat is out, glory to God, like if it's going to inflame."

She referred to prolapse as a piece of "meat" coming out of her uterus in order to explain why she was bleeding. Perhaps she meant to further assert that her condition was severe, but the verbal illustration she was providing suggests that she might have seen this experience closely somewhere, indeed, Nabeela indicated that her mother had prolapse. The following theme discusses what Nabeela said about her mother's experience and examine how it had impacted her own experience.

Theme 2: Experience of mother:

This theme discusses the experience of Nabeela's mother from her perspective and highlights the differences and similarities between them. Nabeela spoke about the reasons she thought her mother had prolapse, which were different that the reasons she has given for herself to develop the condition. She also spoke about the management approaches her mother used as treatment and their effectiveness, and finally moved to what she thought actually healed her mother from prolapse.

Nabeela said that her mother also had prolapse and she spoke about her experience. She said that her mother's condition was eventually managed through hysterectomy and Nabeela perceived that her mothers symptoms were much worse than her own.

"for 35 years it was descending and her condition was worse than my mine!"

Nabeela further provided a description of what her mother's prolapsed uterus looked like by the time she was about to have hysterectomy, she said:

"but I swear when they removed it out it was as black as my scarf, I even saw it with my bare eyes when I was staying with her when she was admitted at the hospital. (Pause) They removed her uterus when she was admitted at the hospital and it looked like my Abaya, but I swear it was black because of how sick she was"

She described her mother's prolapsed uterus to be black in colour and resembled it to the black scarf she was wearing during the interview, but she had seen it as she was staying with her mother at the hospital, and this possibly justify the description she provided of her own condition which was discussed in the theme above. It was felt that her mother's experience perhaps shaped her perceptions about what prolapse looked like. Nevertheless, Nabeela felt that she and her mother had developed prolapse for different reasons. She said that her mother had it as she had been living a restless life and was involved in heavy duties.

"And from heavy lifting and putting, they used to carry goatskin filled with water, grind barely to make flour themselves until this problem comes out, they used to log for firewood, I mean my mother had this because of hunger and restless life, everyone for hunger and restless life and heavy lifting."

What Nabeela said reflected her perception of life in the old days, she spoke about specific reasons that were an indication that her mother indeed was a living a restless life. But her perceived causes for herself to have prolapse appeared to be different than causes she linked to her mother's condition. By saying "everyone" Nabeela felt that all women of her mother's generation had prolapse due to their lifestyle. Nabeela then compared her lifestyle to her mother's lifestyle in the old days and she said:

"I, I swear, no woman do it now these days, I never do it. I am not like my mother even! I am living a blissful life praise to God since the day I knew I exist!"

Despite she felt that her uterus prolapsed after doing some work around the house and considering it as a potential reason, however Nabeela felt that she was living a blissful life. It seemed as she might was underestimating the work she has been doing around the house and compared it to what her mother has been doing and this could explain why she thought that it was God's will for her to have prolapse rather than asserting that the work she has done that day was the reason, she continued:

"And even in the old time no one cared about someone when he gets sick even if he was dying, if someone told them that he or she is sick they would tell him get up and go work! Praise to God we are living blissful life now, unlike the old days."

She further said that she was living a blissful life and her perception seemed to be influenced by her mother's lifestyle that she thought was restless. Nabeela also reflected on people's response to illness in the old times. She said that people cared less about one's health and were expected to carry on their work even if they were sick, but she also indicated that there were no doctors at that time and people had to manage their condition by themselves. Hence, Nabeela said that her mother also had to do so.

"In the old days there were no doctors, people in the rural areas used to pull her and hang her on trees so the uterus elevates so she can pass urine"

It was not clear whether this was Nabeela's lived experience or if this was what her mother told her, but she seemed confident and certain while giving such statements. Nevertheless, her discourse suggests that her mother at first had to manage her condition through traditional medicine approaches as perhaps there were no available healthcare services.

"the traditional medicine was here for a long time, my mother was treated by them when she first had her descend, they told her you must take a rest and lay on your back, but my mother's she never listen to them, people in the old times used to do a lot of work but never rest, people were warm blooded"

Traditional medicine seemed to be the only way of managing healthcare problems in the old days according to Nabeela's narrative. She said her mother was advised to rest but she never listened, and Nabeela felt that it was because people were used to be active and restless back in those days. But there seemed to be a strong belief that traditional medicine broadly was the cure for all healthcare issues, and she perhaps thought that it might have worked with her mother if she agreed to rest for a while.

"its women long ago, I had my mother, she died a while ago, and she always said the traditional medicine was good for everything."

Later in the interview, Nabeela said that her mother was taken to the hospital to have hysterectomy which contradicts her given statements that there were no doctors around. However, she said that her mother lived with prolapse for 35 years, it could be that around the time she first had it there were no official healthcare services in the area she was living but it was available many years later.

After having a hysterectomy, Nabeela said that her mother was treated from prolapse or "healed" as she chose to say. But Nabeela did not seem to think that she was healed because she had the surgery, rather she thought it was because her mother was a kind person.

"what healed her out of it? her kind heart and good intentions, a human that is so kind"

It felt that her perception was informed by some religious beliefs that she might be holding, this is explored later on under the theme (cultural and religious perspectives).

Theme 3: Traditional medicine experience:

Traditional medicine was the first type of external support Nabeela sought. This theme explores the effects and effectiveness of traditional medicine in managing Nabeela's symptoms.

Nabeela seemed to follow her mother's route in terms of prolapse management. As her mother told her that traditional medicine was helpful in managing all healthcare problems, Nabeela first sought traditional medicine support where her symptoms were confirmed to be as a result of a prolapse.

"when she came to see me, and she confirmed that my uterus is descending extremely descending."

It felt that the traditional medicine practitioner was the first one to provide Nabeela with the diagnosis of her condition. She then spoke about the management that was given to her and its effect, she said:

"when the traditional medicine doctor rubbed my tummy the uterus was elevated, it was helpful for the 1st day then it started descending again lower and lower" Nabeela said that it has been helpful for a couple of days then she felt that the symptoms were back again, which suggest that it was ineffective in managing her symptoms.

"My uterus has descended, and I called a traditional medicine doctor to rub me, but it did not work"

But Nabeela seemed to be looking for an explanation as to why traditional medicine was not effective, she felt that she needed to rest so that the traditional medicine could have an effect.

"but I swear I keep myself busy, and a lie down a little, maybe I need rest!"

What Nabeela said felt contradicting to her perception of her life as blissful. Moreover, it could be that it was hard for her to simply say that it did not help as it was rooted in her beliefs that traditional medicine was helpful for everything. Nevertheless, as deemed ineffective, Nabeela's next option was to seek healthcare support and her experience is discussed in the following theme.

Theme 4: Healthcare experience:

This theme discusses Nabeela's experience with healthcare. She sought support at two different healthcare facilities, in the first one she was given analgesia and in the second she was advised to have a pessary as method of management; hence, her perception of feeling very ill was contrasted by the doctor's opinion. Nabeela also spoke about difficulty in access to healthcare and her understanding when hysterectomy would be necessary.

Nabeela sought healthcare support after trying traditional medicine which was ineffective in relieving her symptoms. She said the doctor checked her and said that there was nothing wrong with her.

"about a year ago, I swear I came here and I had an appointment with Dr, (I). I came and said I have this and that, and she said she needs to check me down there, she checked and said nothing is wrong with She felt that what the doctor told was contrasted to how ill she perceived herself to be and she did not seem to be happy about it as she said:

"Anyhow, when I came for the re appointment, they wrote that I was sick, I'm not just sick I'm in so much pain, even sitting I can't sit! I feel my uterus is extremely descending and sometimes I see blood coming out with it."

She possibly felt that her problem was being underestimated by the doctor which perhaps would give her less priority in terms of appointment or the care she would receive. Indeed, Nabeela was asked to make another appointment for managing her prolapse.

## "she told me to reschedule so she can place something inside to hold the uterus"

Nabeela was advised to have a pessary as a method for managing her prolapse, the doctor seemed to have explained to her how pessary works as Nabeela said:

"She said she will tie a plastic inside my uterus, and this plastic even might fall out, and if it falls, if I wash up for praying and it falls out I pick it up and through it back inside! How can I through it back inside? Have you heard about it before?"

It was apparent that Nabeela was unable to make sense of the pessary because it was new to her. It felt that Nabeela did not fully comprehend how pessary works and her discourse suggests that she felt it was something unstable as she was told that it might occasionally fall out. She further seemed to look for confirmation that there such method to manage prolapse, it is possible that this was because her mother never had pessary before, and Nabeela seemed to want to try the management approaches her mother had in the same order.

But despite her understanding of the pessary, Nabeela said she went to see the doctor to have the pessary, but she attended without making an appointment and was unable to be seen by the doctor.

"I told her I will come on Sunday, but I came earlier in the same week, she said she would do it but her working hours on that day were from 8 to 10 in the morning and I was there in the afternoon"

Nabeela indicated that she faced difficulty in making appointments firstly because it is done by using the internet, secondly because she was unable to find any recent appointments.

"even making the appointments here is hard, my daughters have been looking how to make appointments and they said everything is by using the internet, and they made me the appointment through the internet and I find that the appointment is in a year and a half!!"

Her dependence on her daughter to make the appointments could suggest that Nabeela had limited digital literacy which perhaps explains why she perceived the process to be difficult for herself. Difficulty in access was also noted when Nabeela spoke about going to the hospital, she was depending on her son to take her to hospital which she thought was far from her home.

"I swear it's a long-distance driving from my home to the hospital and the way back but you guys never believe me when I say that"

She also added:

"My son always tells me it too far and long drive just to drop me here for half an hour appointment"

Nabeela seemed unable to make the appointments by herself, could not find any recent appointments, and depended on her son for transportation. These factors could possibly explain her behaviour when she attended the clinic with no scheduled appointment. This lack of engagement with modern technology could underpin why she sought support of traditional medicine and then went to a clinic that was close to her house where she was given medications for relieving pain, which was not helpful but perhaps triggered her to seek support at a hospital.

When Nabeela sought support at the clinic that was close to her house the doctor told her that she would not be eligible for hysterectomy unless she had fibrosis or was at a more advanced stage of prolapse.

"She said the most important thing is that there should not be fibrosis, the doctors will not remove your uterus unless there is fibrosis or it is extremely descending, as she said the most important thing that there is no fibrosis so far, but it is very descending for me."

While narrating this, Nabeela was asserting her perception that her uterus was extremely descending. It could be that her main motive to seek healthcare support was to have hysterectomy similar to her mother as her perception was that she was very ill of prolapse. Nabeela also asked to be referred to another hospital, it is possible that because the doctor did not confirm that she was extremely ill and suggested pessary as a management, Nabeela changed hospital aiming to be offered a hysterectomy.

#### Theme 5: being old:

Nabeela said a couple of times that she felt she was an old woman; the first time was when she wanted to say that pessary was not a suitable option because she felt she was an old woman.

### "I said it might fall out and I am an old woman"

The second time was when she was talking about her sex life and said that she and her husband no longer had sex as they were both old.

## "Well, he is an old man and I'm an old woman, I'm just concerned about this what is obstructing me.

It was not clear on what basis she defined herself as an old woman but gave her indication for referring to her husband as an old man. She felt that he was not interested in women anymore, used an assistive device to walk, and had a "grey beard", and for these reasons she perceived him to be an old man.

"My husband is old, he no longer seeks women at all, he is very old, very greybeard, he uses a cane, he still walks a bit using a cane but he is really old, praise to God."

Her narrative could reflect her own understanding of being old. It is possible that her perception of herself as an old woman could be for similar reasons, it could be that she was no longer interested in sex and had grey hair. Moreover, Nabeela indicated that her mother had prolapse, it could be that she saw her mother complaining of symptoms while she was much older than her but having prolapse meant that she was an old woman because she perceived her mother as an old woman around that time.

Nabeela said that she stopped having sex many years before having prolapse possibly for reasons related to her husband and perceived that it was god's will for her to have prolapse.

"It has been like this 7 or 8 years ago, before my uterus descended and we stopped sleeping together. (Pause), but it's God's will to me to have this, but I'm telling you he is a really old man."

Her narrative suggests that she perhaps was relieved that she did stop having sex before having prolapse as it might have posed further problems.

Theme 6: Cultural and religious perspectives:

This theme demonstrates Nabeela's unique cultural and religious perspectives that were evident during the interview.

Nabeela's overall narratives reflected cultural variation in the old times back when her mother was young and her perception of lifestyle nowadays. Her discourse suggests that she felt there were different expectations from women in old days, and at times it felt that she was underestimating the role of women of her generation. She said that life was restless, and people were often out of food and basic life needs, and they would continue doing their work even at times of sickness which caused her mother to be extremely sick because of prolapse. It was not clear which time era Nabeela was speaking about, but it was apparent that it was around the time when Saudi Arabia was not a rich country.

When speaking about her experience of healthcare, the issue of dependency on children was brought up. Nabeela depended on her daughters to make her appointments and on her son to take her to hospital. There seemed to a familial bond that she as a parent was somehow dependant on her children. This issue is culturally common that children after growing up should be carers for their aging parents. But depending on her son solely to take her to hospital was perhaps because of the male guardianship law and that women were prohibited by law to drive cars. Both laws have been cancelled but it is possible that it left some traces on Nabeela's experience. Indeed, Nabeela said that she would ask her daughters to help her with housework but did not mention if she would ask her sons to do so as well.

Nabeela's religious beliefs also emerged as a theme during the interview few times. She mentioned few causes for having prolapse but then said that it was God's will for her to experience it. She appeared to accept prolapse as if she was destined to have and perhaps being Muslim meant she was obligated to accept life events: happy or sad as fate and was religiously prohibited to question why it happened or link it directly to other reasons.

When speaking about her mother's experience with having hysterectomy, Nabeela said that her mother's kindness and good intentions were basically the reasons why she was healed. This perception also seems to be relevant to Nabeela's religious beliefs as these two qualities are valued in Islam and there are many religious texts asserts that the reward of kindness is kindness and that good intentions bring nothing but good to people.

#### Conclusion

Seven themes were generated out of Nabeela's transcript, the themes were all connected. what was unique about Nabeela that her understanding of prolapse was built through comparing her experience of prolapse to her late mother's experience of prolapse. Salwa:

Generated themes:

Theme 1: Family:

This theme represents the position of family broadly in Salwa's life. This theme deemed to be the first theme as Salwa had two medically trained children in her family: one physician and a dentist; hence, it could be argued that their impact on her experience of prolapse would be inevitable, but it was not the case here.

Salwa said that she herself was a medical student for few years but gave up her education after getting married.

"I am the mother of Dr, (A). (Pause) I studied medicine for two years then I got married and did not continue, and my children continued on my behalf. (Pause) I have a son who is a doctor (Mashallah), and the rest are engineers."

She then indicated that her children continued studying medicine on her behalf. Her discourse suggests a number of possible things, it could be that she resigned medical school as she got married and the subsequent responsibilities associated with marriage. Moreover, it is also possible that this decision was expected from her as a wife which could imply that there was some sense of regret.

She further said that one of her sons is a physician and her other children were engineers and earlier mentioned that her daughter is a dentist. The way she expressed her above narrative could imply that she was proud of her children, indeed she started off the interview by defining herself as "the mother of Dr, (A)" who attended the appointment with her but was a dentist. Salwa did not discuss how she shared her experience of prolapse with her children and how having a physician son impacted her experience which could be because of gender related issues. Theme 2: Understanding of prolapse:

This theme demonstrates the knowledge Salwa had about prolapse. There have been some l contradictions in her narratives in terms of understanding of prolapse. Salwa said she had no knowledge about her condition but some knowledge evident during the interview, particularly that prolapse could be attributed to a number of factors. This theme further represents the effects of prolapse and the implication it had on Salwa's life.

Salwa first said that she had no knowledge about prolapse.

"I know nothing about it."

But later during the interview, she mentioned certain risk factors that she perceived they have caused her to have prolapse.

"but it is the advancing in age what brings it, increased pregnancies and labours"

Salwa's discourse suggests that she felt prolapse was part of aging and she also linked it to childbirth. By saying "increased pregnancies", it felt that Salwa might have thought getting pregnant six times was a lot; hence, having prolapse was inevitable. She sounded assertive when mentioning these risk factors, despite indicating first that she had no knowledge about prolapse. This contradiction might be explained by the possibility that when saying that she knew nothing about it, Salwa might meant to say she personally had no previous knowledge, yet it was maybe acquired or developed as she sought healthcare support at another hospital when her urinary symptoms started. Moreover, Salwa shared her experience with women around her, this is explored later on, but it might have impacted her knowledge. In addition, Salwa said her son is a doctor and daughter is a dentist, it is possible that they might have provided her with some information about prolapse. She might have gained her knowledge from different resources and might be uncertain of the information she had about prolapse. The knowledge Salwa had was at times evident as she spoke about the implication of prolapse on her. She stated that she felt "bothered" while walking and indicated that it was also relevant to drying.

## "I feel like something is coming out of me, and it bothers if I walk, and also because of drying."

It was not clear what she was precisely referring to, but as she was speaking in the context of pelvic organ prolapse, it is possible that it was vaginal dryness that she was referring to. Salwa did not say she had vaginal dryness but linked her bothersome while walking to prolapse and vaginal dryness. Her certainty could imply increased self-awareness but also could be informed by the knowledge she gained about prolapse but refused to acknowledge.

As she further spoke about the effects of prolapse, some level of knowledge was also occasionally apparent. Salwa said that she felt disturbed by her condition during intercourse and standing for long time. But she also said that she did not complain of the other common symptoms of prolapse such as pain and bleeding.

During intercourse, and if I stand for long period of time, I feel tired, but praise to God I don't have any pain because of prolapse, no bleeding, no discharge, and no pain"

#### Theme 3: Manage and control:

This theme discusses the methods Salwa used to manage her condition and control the progression of symptoms. Her decisions seemed to be informed by women around her like her sisters and friends.

Salwa tried a couple of ways to manage her condition and control the progression of prolapse symptoms. She said that she has tried seeking the support of traditional medicine.

"they told me there is one Asian masseuse, but I swear I don't like these things, I brought the Indonesian and she did a massage for me as you would say, lifting and massaging, I don't remember doing anything else." Salwa has mentioned that she felt bothered with walking and standing, this deemed problematic to her because she said she used walking as an exercise and also went to the gym. Salwa however simply decided to stop walking a lot and cancelled her membership in the gym as she felt that this would stop her condition from progressing.

"I used go to the walking path, I also was registered to a gym, and then I stopped because I heard that it affects the prolapse, and it's also affected by walking, so I stopped going to the walking path and the gym after the problem started."

She continued:

"It already bothers when I am standing for a long time, maybe when I am walking or at the gym it might come out more."

Salwa also said that prolapse caused her to feel bothersome during intercourse, and she also stopped having sex since having prolapse because she felt it would control the sense of "bothersome" she was having during intercourse.

# "Yes it bothers me, but I have stopped intercourse since the problem started"

Her response towards her condition could propose that having an active lifestyle or an active sex life was not important to her. Choosing to stop exercising is a personal decision but in terms of sex, understanding the response of her husband is important to clarify why she had taken that decision. This is further discussed under the next theme.

When speaking about stopping exercise, Salwa said "I heard if affects prolapse", she did not say who she heard if from but it is clearly from people she shared her experience with, it could be her children, sisters or friends. Moreover, the decision to seek a traditional medicine practitioner was indeed informed by her sisters and friends as she was told that her uterus was inverted.

"I brought her because they said your uterus might be inverted, bring her she is good, she lifts and I don't know what." Perceiving prolapse as inverted uterus might be an illustration of downward descent of the uterus, and she was told that it needed to be lifted up by traditional medicine massage. Salwa indicated she did not believe what she had been told yet decided to do so because her sisters and friends told her about traditional medicine.

## "I swear my sisters and friends told me bring her, you know she gave them her number"

Salwa said that she did not feel that traditional medicine was effective in managing her condition. Salwa relied on her sisters and friends in her decision to approach traditional medicine despite having a medical doctor son, and then said she did not believe in traditional medicine. It could be that the influence of women in her context in informing her decision was greater than having a son who was a physician, or it might be hard for Salwa to discuss prolapse broadly with her son given that he was a man, this is further explored under the theme "religion and culture".

Salwa stated that she waited for six months until deciding to seek healthcare support for prolapse and used her coping strategies instead. It could be that what she has been doing so far in terms of stopping sex and exercise in terms of controlling her symptoms has been working for her until she started to have recurrent urinary tract infections or maybe her prolapse symptoms progressed despite her attempts of control which might be the reasons why she decided to seek healthcare. This is further examined under the theme "healthcare support"

#### Theme 4: Sex:

This theme shows Salwa's perception of sex and the factors she thought to control sex life, which justifies her immediate decision to stop having sex since she had prolapse.

Salwa said that she stopped having sex after experiencing prolapse. She then shared her perception of sex. She felt that the importance of sex was gender specific saying that it was important to men. She also added that her husband had his own reasons for not having sex. "Intercourse is important for men but he also has other reasons (Pause) you know advancing in age (Pause)"

It seemed that Salwa thought the sex was not important to women, or not important to her personally. In terms of her husband, she first said aging was the reason why he no longer slept with her but elaborated that her husband was impotent and felt that this too was linked to aging.

"You know, my husband is around 70 years old, and you know with advancing age an individual develops sexual weakness "impotence".

Salwa thought sex was important to men but did not directly say it was important to her husband. She then followed up by stating that her husband has health issues that she thought were related to his age. Salwa's decision to stop having sex would not be easy if her husband did not have his own reasons for not having sex. Hence, the decision might be mutual.

Salwa chose to say "an individual" rather than saying that her husband was impotent. Salwa considered impotence to be a normal part of aging for men. Moreover, as she was talking about the causes for which she had prolapse, Salwa said that advancing in age was one of the reasons. Hence, her narrative about her husband's age and sex could be reflecting her view towards herself that she also was growing old and having a problem that was affecting her sex life.

Theme 5: Healthcare seeking behaviour:

This theme discusses Salwa's experience with healthcare support starting with her potential reasons for delaying seeking support to the possible factors that triggered her to do so. Her responses towards treatment methods are also discussed here in addition to explaining her feelings of fear when she was told to have hysterectomy.

Salwa said that she purposely chose to wait to seek healthcare support, but she eventually had to do so as she started to feel bothered by symptoms.

"I have waited a while, I mean at first it was only bothering me a bit, and then at last I started to feel that something is coming out and it started to bother me more honestly like 5 or 6 months after" Over the period of six months, Salwa said she felt more bothered and decided to seek healthcare support. Her narrative suggests that her rational for delaying to seek healthcare support was because she was not much bothered by her symptoms. Moreover, Salwa has attempted to control the progression of her symptoms that did not seem effective after couple of months then she decided to seek healthcare support. Salwa said that the prompt for seeking help was that she felt bothered because her uterus was out and had urine infection, she was advised to manage her urine infection issue first.

"The urine problem is the most bothering one, so the doctor told me to end this problem first and has given me antibiotics for it, and about the uterus, she said 2nd or 3rd degree prolapse I don't know what, but I mean uterine prolapse"

The symptoms of the urinary infections had been more disturbing than the prolapse to Salwa; hence, it is possible that Salwa essentially decided to seek healthcare support because of her recurrent urine infection problem otherwise she seemed to be managing (and living with) and controlling her prolapse symptoms. Nevertheless, Salwa first sought healthcare support at a private hospital and the doctor identified that she had second or third stage of uterine prolapse and then said that she might also have other problem.

"the doctor first told me that you have uterine prolapse, and then she said your uterine wall is enlarged, we will do a scope"

Salwa said that the doctor told her that she might have uterine wall enlargement, the doctor said she would do hysteroscopy to further investigate the issue. But Salwa refused to do the procedure and decided to seek the opinion of other doctors.

"I did not agree on doing scope and said to myself to consult more than a doctor and see"

"Yes she said she wanted to check the uterine wall, it might be enlarged she said, but I couldn't although she has written it on my file, so I said to myself I come to the university hospital and consult the doctor here" But in terms of urine infection, Salwa was given antibiotics and she accepted it as part of treatment and did not seem to consult other doctors in this respect.

"I started to have urine infection, and then she performed a urine culture, and I still have the infection so she has given me antibiotics, I have had my last antibiotic today"

When Salwa spoke about the causes of prolapse, she assertively said that it is a problem caused by advancing in age and childbirth suggesting that she was normalising prolapse as part of aging and result of pregnancy and childbirth. But when she was told that she might have uterine wall enlargement and her response to the suggestion of having hysteroscopy could imply that Salwa was looking for a doctor who confirm her potential perception of prolapse as something expected rather than telling her that it was something problematic, and her choice of hospital could be because her children were working there as healthcare professionals.

The doctor's suggestion of undertaking a hysteroscopy made Salwa feel scared, but she did not share her feeling of fear clearly during the interview as she did not say it directly, she first said:

"But when she told me enlargement or I don't know your uterine wall is thick, you know human gets a bit scared, you know when someone feels (Pause)"

She chose to say "human gets a bit scared" rather than referring to herself and saying that she was scared, when asked to further clarify, she added:

"Meaning feels scared that, God forbids, something like, meaning operations and so."

She said that she was afraid of having an operation, and then she continued:

"but I mean something like this in the uterus, the uterus gets removed, meaning they extract the uterus if there are some cells"

Salwa was afraid of the possible findings of the procedure, she did not say it clearly, but it felt that she was concerned her condition would be more serious than

prolapse. The doctor's request to do further investigations perhaps caused her to be afraid that her condition was serious, which contradicted with her perception of it as part of aging.

Salwa's fear could suggest limited understanding about the procedure and the need for it. She said that the doctor did not explain her condition to her and Salwa did not ask her about it either.

## "I haven't asked her anything nor did she tell me anything."

There seemed to be limited understanding due to apparent lack of communication, she did not say this though. But when Salwa sought support at the hospital she was accompanied by her son who was a physician himself and Salwa said the doctor was discussing her condition with her son rather than speaking to her personally.

"my son was with me that day, he sat and obviously he is a doctor and was discussing with him, in that hour I understood that she is doing a scope, and the scope will show is it enlarged cells or not"

Her narrative indicates that her doctor did not directly tell her that she needed to have hysteroscopy to further investigate her problem, but Salwa heard that as she was speaking to her son, and this left her afraid and need for comfort.

Theme 6: Cultural and religious perspectives:

This theme represents some of the perspectives Salwa shared during the interview that seemed to be informed by her cultural and religious background. Her discourse highlighted certain gender ideologies and reflected on family dynamics particularly between parents and children.

As Salwa was speaking about the implication of prolapse on her sex life, she indicated that she stopped having sex since she had the problem because she felt "bothered". She further said that her husband did not mind because he already had his own barriers. But she also pointed out that sex was important for men. This might be relevant to the common gender ideologies that are informed by her cultural background. Sexual capabilities of men and women are constantly compared, and it is often concluded that capabilities of men are greater than

women's; and therefore, some assume that men are allowed to have up to four wives for this reason. But Salwa's husband had some health problems that limited him from having sex, hence this might have contradicted her perception.

Salwa said she had no knowledge about her condition, despite the fact that her son was a physician. She did not indicate if she discussed her condition with her son or if he tried to explain it to her, but her narratives suggested that they did not. This was evident when Salwa's doctor informed her son that she might need to have hysteroscopy and Salwa said she understood this rather than her son told her so. This could be relevant to cultural gender ideologies; indeed the sensitivity of the condition makes it hard or taboo to discuss it with opposite sex.

When introducing herself, Salwa said that she was a medical student who did not continue her education, but her children did on her behalf. This possibly implies that their success in life is perceived as her own success which could demonstrates the family dynamics in Saudi Arabia and the responsibilities parents have towards their children and the other way around. Some parents, particularly mothers, often give up their education of career by choice to look after their families and after their children grow up, they have to look after their parents. And this was the case with Salwa, when she sought healthcare support, her son would take her to hospital and be closely involved in her condition.

Salwa's religious beliefs were also evident occasionally during the interview. She was thanking God over and over when talking about her condition despite being disturbed by symptoms. This is perhaps grounded in her beliefs that she had to be thankful to God even in worst life circumstances as it could have been worse. Moreover, when Salwa spoke about her decision of refusing hysterectomy and consulting other doctors, she said:

## "And I did want to do it and I prayed God and asked him to choose for me and said let me go see another doctor"

Salwa seemed to be talking about the concept of "Istikhara" in Islam which directly means the prayer of seeking counsel, it is the prayer of asking god for guidance in terms of action concerning life aiming for the best possible outcome. Respectively, one should feel a sense of peace and contentment with their decision if it inclined with God's choice, and if opposite, one may feel doubtful, apprehensive, and averse to moving forward with his/her matter. Salwa decided to refuse a hysteroscopy and asked for God's guidance and perhaps she felt that God has indeed helped her as she was at the hospital to be seen by another doctor and this might have provided her with sense of peace and comfort.

#### Conclusion

The analysis of Salwa's transcript resulted in generating six themes. Salwa's past experience as a medical student and her medically trained children did not inform her current experience of prolapse, rather it was greatly influenced by her societal background.

Zainab:

Generated themes

Theme 1: Understanding of prolapse:

This theme demonstrates the effects prolapse had on Zainab. It also shows the knowledge she had about her condition. As her prolapse had been managed using pessary, Zainab spoke about the effects prolapse had on her. In terms of knowledge, it was evident that Zainab had no previous knowledge about why she developed her condition and did not provide any possible risk factors that she perceived could have caused her prolapse.

Zainab's experience with prolapse started six years ago, she started the off the interview by narrating what she felt when she first noted her uterus descending.

"I mean at first when it started about 6 years ago, I was so scared, I didn't know where to go! I said maybe I have cancer, it descends more and more, more and more every time, I don't know why"

She indicated that she felt scared and was concerned that it might be cancer. Relating her condition directly to cancer without considering any other possible health issues and wondering why it grew bigger reflects that Zainab had no previous knowledge about prolapse. Her discourse suggests that she felt lost particularly when she said, "I did not know where to go". It also demonstrated that she did not know whether this problem required healthcare support or maybe she did not know who she could speak to. Nevertheless, Zainab said she tolerated the symptoms for a while until she sought healthcare support. Around that time, Zainab started to feel that her uterus was descending when she walked or used the toiled and perceived herself to be sick.

## "when I urinate my uterus really descends, and when I walk, I am sick"

She was describing prolapse as sickness. This was said when Zainab sought healthcare support in the UK and was telling the doctor about her condition. Her experience of healthcare support is discussed in the theme below.

Healthcare support in the UK:

This theme represents Zainab's experience with healthcare in the UK. She was advised to have a pessary as a method of management. Zainab said she visited the UK because her daughter was studying there. She sought healthcare support while she was in the UK and said the first management option discussed was to have hysterectomy. Zainab said the doctor did not prefer it as she thought that Zainab was not at the age where hysterectomy would be a suitable option.

"they said they remove the uterus, but she said it's too bad if I remove the uterus you are not that old, there is another solution, I said what is the solution? She said there is a ring that we place in you"

She was narrating her first experience with healthcare and that the doctor then spoke to her about pessaries to support her uterus as she though Zainab was not an old enough for surgery. The doctor placed the pessary and it was unchanged for three years, then Zainab returned to the UK and visited the same doctor to change it.

"she changed the ring for me, and another one after 4 months, and I was staying at my daughter's did not travel, but this time the it was

## big, it was hurting me it wasn't properly fitted, we called them and they told me to come"

This time Zainab visited the doctor many times because she said she was staying in the UK with her daughter, and Zainab said there was a time where she felt that the pessary was not properly fitted. She did not say what made her feel that way, but she said it was causing her pain; thus, she felt that it was misfitted. However, Zainab spoke to the doctor, and she asked her to visit the clinic to change the pessary. This event suggests that Zainab might have thought the access to healthcare was easy in the UK given that she has been to the clinic a couple of times. Zainab further stated the doctor's response when she spoke to her about the perceived misfitted pessary.

"I went and she said it is a bit bigger my mistake, I will place a smaller one, and she placed a smaller one and I bought some from them"

It felt that Zainab was saying that the doctor acknowledged her mistake and said that she had placed a bigger pessary and told Zainab that she was changing it to a smaller one. Zainab did not speak about her feelings about her experience and how it impacted her symptoms, but she appeared to be satisfied with using pessaries as a method of managing her symptoms as she bought pessaries from the UK because she was flying back to Saudi Arabia, and she perhaps wanted to continue using pessaries. The following theme discusses her experience with healthcare services in Saudi Arabia.

Theme 2: Healthcare support in Saudi Arabia:

Zainab's experience with healthcare in Saudi Arabia is discussed in this theme. It demonstrates her journey of finding a specialised physician to change her pessary. Her journey began with seeking support at private sector that Zainab perceived to be unpleasant, then deciding to remove the pessary, and finally finding the specialised urogynecologist at the governmental hospital where she was satisfied with the care she was provided.

Zainab narrated her experience with healthcare in Saudi Arabia, she said she started to go to a polyclinic that was close to her house. Broadly, polyclinics in Saudi Arabia are private clinics that offer paid healthcare services. Zainab sought support in order to change her pessary, and she did not mention the doctor's response to it or whether she suggested different approach of management. Nevertheless, Zainab's experience at the polyclinic seemed to be unpleasant to her.

"when I came back here I used to go to a polyclinic near our house, to a woman doctor to place it in me, I seek refugee of Allah! Sometimes I bleed, the same ring! The same size! I don't know how! She did not place it properly, what shall I do she said wait I will check and do some tests for the uterus, so she did an re placed it, and then a lot of dirt started to come out of me with a very disgusting smell!"

By saying "I seek refugee of Allah", her choice of words suggests that it was a terrible experience. Indeed, this metaphor is often used when talking about something distressing that one would never want it to happen again. Zainab seemed surprised that she was having some complications after changing the pessary and perceived that it was not properly placed. But when she spoke to the doctor, the doctor asked to do some tests and check-ups. Zainab seemed unhappy when talking about her experience at the polyclinic. In the UK, when Zainab felt pain and perceived that it was misfitted, her doctor there owned the responsibility of her mistake and acknowledged that it was her fault. But in Saudi Arabia at the private clinic, the doctor's response was different than the response she seen from her doctor in the UK.

Zainab did not say whether she has done further tests to investigate what was going on. But as it was a private clinic, doing tests meant that Zainab would pay for those tests and also pay for each visit, this could explain why she speculated her intentions as Zainab thought that the doctor was purposely misplacing the pessary so she would visit her often and perhaps she would make money out of each visit.

"the woman in the polyclinic when she placed it I had bleeding with it, I don't know what is wrong with this woman, maybe she wants me to come a lot to see her" Zainab then asked the doctor to remove her pessary because she felt it was not easing her symptoms and was causing her to have pain and bleeding believing it to be misplaced.

"And then I told her take it out I don't want it, she took it out and then I was so so sick in Ramadan, I used to cry in Ramadan, just like that the uterus comes out of me (fist), it tires me when I am walking, when I am working, I wear diapers and two underwear and pants when I walk so it doesn't tire me"

Taking the pessary out did not relieve Zainab's symptoms, she said she was in pain afterwards and felt that all her uterus was out. It took a while until she decided to put it back again. It was however noted that Zainab referred to the doctor at the poly clinic as a "woman's doctor" and Zainab perhaps meant a gynaecologist. Deciding to remove the pessary rather than seeing another doctor immediately perhaps suggest that it was difficult to find a urogynecologist who was specialised in managing such conditions. This also emerged as an issue when Zainab spoke about when her son found her current doctor, and also referred to her as "woman's doctor".

## "he said look I have found you a woman doctor who is really good"

She sought support again after he found the "woman's doctor", suggesting she was waiting to be seen by a specialist urogynaecology physician. Indeed, it was earlier mentioned that Zainab said when her symptoms started that she did not know where to go, which could mean that she did not know where she could find a specialised urogynecologist.

Zainab sought support with the doctor that her son found for her at a governmental hospital. She seemed to be pleased with her experience and indicated that she was happy and comfortable.

"and now every day I pray for her, nothing at all comes out of me, no dirt no smell no nothing, and I am soo comfortable, I am so happy since I have done it, and now it did not come out but I said maybe it is bad if it stays for long, she placed it first 7 months ago" She further said that she was at the clinic to change her pessary as it has been placed seven months ago, her trigger was that she was concerned that it would be harmful for her if it stayed longer. But when Zainab had the pessary placed in the UK initially, she kept it unchanged for three years and said that she did not complain of anything except for little discharge that she perceived as dirt. She did not seem to have any option other than to keep it as perhaps she did not know where to change it. But considering changing it and being concerned about her health suggests the ease of access at the governmental hospital and that she did not change the pessary for a while.

Zainab indicated that she felt "bloomed" after her gynaecologist put back the pessary to support her prolapse. She said that she felt symptoms free and thought she was able to maintain her daily lifestyle.

"Yes I am very fine, I am not complaining of anything at all, I water the plants in my yard I walk I go to the walking path and walk for 30 minutes every day, praise to god, I lift things, there is nothing wrong with me at all, I work at home, Mashallah Dr, (I) bloomed me. (Pause)"

Zainab perceived there was nothing wrong with her anymore and expressing her feelings this way and using the verb "bloomed" seemed as if she was very dull after her experience at the poly clinic and her decision to remove the pessary and how ill she felt afterwards perhaps made her unable to live her normal life. After being through all this then having a presumably lifechanging experience, Zainab felt perhaps very grateful as she said:

"But after seeing Dr, (I), it's like I don't have the descent anymore. (Pause)"

It appeared that Zainab was pleased with how the doctor at the governmental hospital managed her condition. She said she was not wasting her pessary as sometimes she would take the pessary out, clean it, and put it back in.

Theme 3: Pessary:

This theme shows the effectiveness of pessary in managing Zainab's symptoms of prolapse and her understanding of pessary. Zainab indicated above that she attended the clinic only to change her pessary, she had no complaints suggesting that pessaries were effective in managing her symptoms successfully.

"Its all in, I don't see it coming out when the ring is in. I feel no pain no discomfort praise to god."

She said that she felt no pain or discomfort while the pessary was in, and she indicated that she no longer saw her uterus out which perhaps relived her fear. But when she first had the pessary placed in the UK to support her uterus, Zainab said that she was scared as she had a flight on the same day and was concerned that something was going to happen.

"I was so scared that something is going to happen to me in the airplane, I said I have a device they've placed a device inside me"

Zainab did not say precisely was she was afraid of, but she has referred to the pessary as a "device". Her perception of pessary as a device perhaps gave it another conceptual dimension that it was something that needed to be taken seriously.

Zainab was told that she had the option of changing the pessary by herself every couple of months.

"you change it every 4 months, you can also take it out, clean it, and re-place it by yourself, if you couldn't, every 4 months come see me"

But she kept it unchanged until she seen the specialist urogynecologist in the UK and in Saudi Arabia after her return. And when she asked to doctor to remove the pessary, Zainab did not mention if she tried to change by herself but her journey of seeking support at different healthcare sectors in Saudi Arabia perhaps suggests that she did not, which could be potentially relevant to her perception of pessary as a device.

Theme 4: Sex:

Zainab had an active sex life, this theme discusses her point of view on sex around the age of menopause. Zainab did not want to have an active sex life anymore, but her husband did, and she decided to tolerate sex as she did not have other option because she was concerned that there would be consequences if she did not.

Zainab indicated that she had an active sex life and shared her response towards it. Zainab said that she no longer wanted sex and that she was sick of it but she justified her not wanting sex by relating it to her capabilities and her perception that she was an old woman.

# "I mean I don't want to, that's it! I am no longer capable of it, I am an old woman!"

Zainab referred to herself as an old woman, back in the UK when she was advised to have pessary as a management, it was rationalised because she was not old, and she accepted the advice. Yet she still perceived herself to be an old woman and indicated that it was the reason why she did not want sex anymore.

"Because I am old, I am 62 all my children are grown up to men I have grandchildren, of course I am an old woman!"

She said she viewed herself as an old woman because of her age and because her children were grown up and she had grandchildren. Her discourse suggests that she perceived that there were certain age and social limits for having an active sex life. Perhaps she was embarrassed of her social image as a grandmother. Zainab said that she has tried warning him that it was not good for him to have sex with her:

"He is fine with it, he does not mind, at first I used to cry when he says he wants me I cry. But I tolerate it what shall I do, I tell him it's not good for you either."

It could be that she felt that having sex at this age, given that she perceived herself to be an old woman, would be harmful to their health but felt that her husband did not mind having sex anyway. Nevertheless, Zainab said that she has ended up tolerating sex. "what can I do? I be patient, sometimes blood come out of me when he does it to me I bleed. But what shall I do? I tolerate because I want to make him happy, I don't want to upset him, I am afraid that he might get married and has kids and my kids suffer because of it"

It sounded as Zainab was helpless, she has no choice but to sleep with her husband despite having bleeding as side effects. When she said, "he does it to me", there was some sense of being passive and some level of compulsion. Zainab said she was obligated to make him happy as she was concerned that he might seek another wife because she felt it would have consequences that she though would affect her children. Her concerns are further discussed in the themes below.

Zainab said that her husband did not sleep with her when she removed her pessary because he saw that she was feeling sick. His response could be viewed as empathy that he did not wish to force her but given her previously indicated concerns, it could have placed further burden on Zainab that she had to find a specialised urogynecologist to put her pessary back as soon as possible.

"But when she took the ring out in Ramadan and the uterus was out he saw I was sick so he did not want to have relation"

### Theme 5: Family:

This theme discusses the role of family in Zainab's experience with prolapse. She shared her experience with her children except for the sensitive or intimate details. Her children were involved in her healthcare experiences in the UK and in Saudi Arabia, and she was happy that they were good to her; hence, it deemed difficult for her to accept that having her children caused her to have a prolapse. Zainab's daughter was in the UK at the time Zainab's symptoms of prolapse started. Her sons were in Saudi Arabia with her, but she only sought support when she was in the UK with her daughter and sought support in Saudi Arabia after her daughter's return.

By the end of the interview, Zainab said that she did speak to her children and doctor about the issues she mentioned during the interview.

"May Allah bless you; you are the only one I told these things to, nobody knows about all this, even my doctor and children don't."

But Zainab has sought healthcare support before and received treatment for her condition so speaking to her doctor about her symptoms was inevitable. nevertheless, she appeared to mean that she did not share her experience and concerns about her sex life even to her children who were clearly involved when she sought healthcare support. This perhaps is because she was essentially perceiving herself too old to have sex and did not wish anyone to know this.

Zainab spoke about her children's involvement in her healthcare experience. To begin with, she sought support in the UK because her daughter was there, and Zainab said that she and her daughter went to the hospital together.

"I travelled to the UK my daughter used to study there, we went to see a British doctor"

When Zainab was back in Saudi Arabia, her son was the one who found the doctor for her.

## "then my son saw Dr, (I) on phone, he said they say she is good, my son is a doctor here"

It appeared that her children were responsible for finding the suitable doctor for her and taking her to her appointments. But when Zainab first had prolapse, she waited until she was in the UK to seek healthcare support with her daughter despite her son was a healthcare professional working at the university hospital. To point out, Zainab has four sons and only one daughter. This could suggest that Zainab might found it difficult to share her experience with her sons and waited to be with her daughter in the UK to seek help.

And when she was asked about the reason for why she thought she had prolapse, she said:

"The doctor in Britain told me that it is because of pregnancies and labours it weakens the uterus." The doctor told her that pregnancy and labour is a potential risk factor for prolapse, and Zainab seemed to agree but she followed that by saying that her children were good to her.

#### "I think that too, but god bless, my kids are good to me all of them."

It could be that Zainab felt that considering pregnancy and childbirth as the reason for why she had prolapse would mean that having her children, who are good to her, to be responsible for causing her condition. And she did not wish to blame them as they were good to her and were perhaps looking after her health; therefore, she was asking God to bless them.

Theme 6: Cultural and religious perspectives:

This theme represents Zainab's unique cultural and religious perspectives that were evident during the interview. She shared her perspectives on men and the power they are socially given and spoke about the meaning of old. Zainab also shed some light on the obligation of children to care for their parents. Religion was also evident in her discourse.

The subtheme "men power" emerged a couple of times during the interview, the first time was when Zainab was narrating her experience at the polyclinic, how ill she felt after she had her pessary changed there and the complications she had afterwards. Zainab indicated that she has a husband while narrating how these symptoms affected her, she considered that the smell and discharge she had was bothering to her husband as they had an active sex life and it seemed that this was concerning her to her.

Zainab's experience suggested that there was power imbalance in her marital relationship. This was evident when she spoke about her reasons for not wanting sex but eventually having to tolerate it as her husband wanted sex. The reasons for which Zainab had to tolerate sex was because she was concerned that her husband would seek another wife. This thought is perhaps rooted in the cultural influence on family dynamics. The religion of Islam allows men to seek up to four wives for different purposes such having more children or when wife is no longer able to have sex as in Zainab's case. She felt that her husband wanted an active sex life

and perhaps if she did not agree, he would seek another wife. But her concerns did not seem to be related to herself or their relationship, rather she was concerned about her children despite them all being adult. Perhaps Zainab's concerns were about inheritance, if her husband got married all his inheritance would be divided between the old family: her and her children, and the new family. Clearly, Zainab did not wish for that to happen; hence, she tolerated sex despite the occasional bleeding she had after wards.

Men power also emerged when Zainab was talking about her husband's health, she said:

## "Otherwise he is older than me he is 70 or more than 70 years old, but mashallah he is healthy and well."

Here Zainab was perhaps rationalising why he wanted to have sex and she did not. In addition to perceiving herself to be an old woman, Zainab had a health problem: prolapse. She indicated that her husband was older than her but was healthy. There is a cultural view towards men that they are stronger than women and able to have an active sex life until a very old age, perhaps age was a factor the Zainab thought would limit women from having an active sex life but not men.

Zainab has referred to herself as an "old woman" and mentioned her reasons for that. She was told in the UK that she was not an old woman, she did not seem to believe that. Her view of herself could be explained by the potential view of Saudi Arabian society towards women at the age of menopause. Women around this age often earn respect of society as being old, from a cultural perspective, entitles one to have status. But it also could be related to religious beliefs, it is a common belief that the mean age for the followers of prophet Mohammed is 63 years old and some may live longer or less. The origin of this belief is unknown, but it could be that Zainab perceived that as she was approaching this age it meant that her life was about to end, and maybe the life span of her family members i.e., parents and siblings was around her current age. Another possible explanation is that she might have thought she has lived her life and looked after her children, and as they were grown up it might be the time for her to finally rest and resign from her responsibilities including sex.

Zainab said that her daughter went with her to the doctor in the UK, and then said her son was the one who found her doctor and told her about her. This reflects that Zainab's children were responsible for the health of their mother, and this is not uncommon in Saudi Arabia as family members are often committed to each other and her children perhaps were obligated to do so.

The religious beliefs Zainab held were highlighted when she spoke about the certain aspects of her life. When Zainab wanted to say she was doing good, she followed it by saying "praise to God". This perhaps reflects that she was being grateful as it often said in the context of being happy in order to thank God, or it is said at times of distress as a way of accepting what happened or being patient. Zainab also said it couple of times such as when she said that she had help at home, when things went smoothly during her first flight after having the pessary, and when she was speaking about her experience at the governmental hospital and how pleased she was. It seems that this was a way of owning the pleasant things in her life to God and that God was the reasons for her improvement, not just healthcare.

Zainab also mentioned God as she spoke about her experience at the polyclinic, she first said "I seek refugee of Allah" and this perhaps meant that she was asking God's help because she was in extreme pain and discomfort and did not wish for that to happen to her again. And then Zainab said "may Allah guide her" as she thought that the pessary was not placed properly, it felt that Zainab thought that she perhaps had no experience or was lost as she did not know how to put the pessary. And Zainab felt that only God can help her through guiding her how to put it.

This metaphor was used again as Zainab spoke about her sex life, she said her husband wanted to have sex and she asked God to guide him. Again, it felt that she perceived he was doing something wrong and only God could help him.

### Conclusion

Seven themes were generated out of Zainab's interview transcript. The themes were understanding of prolapse, healthcare experience in the UK, healthcare experience in Saudi Arabia, pessary, sex life, children, and cultural and religious perspectives. Similar to the previous seven analyses, Zainab's cultural and religious perspectives were overarching in terms of her experience of prolapse.

#### Appendix H: Reflexivity of idiographic analyses

#### Aziza

This was my fourth attempt for analysing Aziza's transcript. The first three were done using IPA, where I had to read the interview multiple times, identify experiential claims and objects of concern, then increase the complexity of the already complex data through writing notes: descriptive, linguistic, and conceptual.

What Aziza said about her experience seemed very common and acceptable. I was able to capture her experiential claims, but they did not seem very unique, and I could not engage fully with her discourse or check my preconceptions as I kept thinking that I knew how she felt and understood what she said, I felt there was nothing needed to be explored. I accepted how things on their face value despite being really close to the data.

Aziza was clearly a religious woman; I am not as religious as her, but I have been to religious schools, and I have been educated about Islamic laws and so. Basically, religion is always there consciously and subconsciously in my everyday practice, I pray five times a day, a thank god at times I am grateful, I pray god to protect my children when I drop them to school, and sometimes when I feel hopeless or something distressing happen I personally accept it as god's will and thank god as it could have been worse.

Being in Saudi Arabia at the time of analysing Aziza's transcript did not make me feel that I have to explore the things she said in depth as I see it everywhere and exploring what she said would mean exploring common beliefs including mine. But when I was asked to write my background chapter, I did some deep reading about religion in Saudi Arabia and how it affected the culture and traditions in the country. As I was critically reading articles that were written by authors who did not share my cultural and religious background, it has been enlightening in terms of the things I perceive normal but were unusual to people who were not familiar with it.

This analysis was done thematically, I read the transcript over and over again, coded the transcript and identified patterns in the data, then extract themes out of

codes. Coding the data felt like doing data reduction, the coded were typed into separate document, then similar codes were connected and made a theme. After producing the themes and subthemes I moved to write Aziza's report. The step of data reduction and moving away from the data a bit perhaps enabled me to reflect on what Aziza was saying and think why she was saying it which aided in the depth of the analysis. The depth could also be attributed to the approach itself and how it has been suitable for my mindset, but it also could be because I have read about the religion and culture in Saudi Arabia and it impacted my thoughts and analysis.

Aziza's reluctance to seek help in her concerns of being exposed is understandable. Prolapse is a highly sensitive topics; hence, management requires approaching the patient subjectively while considering the patient's values and what matters to her.

In terms of hiding and feeling isolated due to urinary incontinence, pelvic floor muscle training is highly recommended for UI. Aziza had willingness to be treated but she was not referred rather she was listed for surgery and delayed a couple of times. Physicians must be prompted to refer women to physiotherapy and the service should be available.

There was a tendency to normalise prolapse as part of aging and a result of childbirth. This asserts the importance of patient education and increase prolapse awareness among women.

#### Dina

Dina was my fourth participant. By the time I was interviewing her I felt I was more able to engage with what she was saying. Her interview gave some deep level of data, she was not hesitant even when she was talking about some sensitive issues related to the problem. Dina spoke to me about her experience in depth although she had lost her trust in healthcare professionals after having unpleasant experiences. I think this could be because I was not involved in her treatment.

Dina and I shared similar cultural and religious background, the expectations placed on Dina as a woman did not seem odd but common in my context and at times normal. The first step of analysis requires reading and rereading the transcript, listening to the interview recording to familiarise with the data, capture unique experiential claims and further engage with what the participant was saying. This step took me a long time as what Dina was saying felt relatively common and acceptable. Hence, when moving to the next steps of analysis and writing the report, the preconceptions I had resulted in a descriptive analysis because I was immersed in my culture. This might be because I was analysing Dina's interview whilst being surrounded by the culture we share.

Stepping out of my culture was both challenging and time consuming but pivotal to produce a critical analysis. This was achieved through basically self-reflecting and acknowledging the differences me and Dina have despite the great similarities. I am a young woman in my early thirties, me and my family "husband and children" have been living in the UK for the past five years where I have earned my master's degree and currently doing doctorate research. Being away from Saudi Arabia have altered the expectations placed on me as a woman to be more westernised, and this has continued even after my return to Saudi Arabia with the positively shifting perspective towards the role of women in the society that has probably resulted from vision 2030.

By bearing this in mind, I started to look differently at the data that Dina had given me and had mixed feelings about her roles and commitments towards her family, and also her behaviour towards healthcare. To begin with, I thought of Dina's commitment towards her family as a job rather than a responsibility, where her husband was the manager who granted her the open vacation. The imbalance in their relationship made his understanding of her condition vital so she could take rest, and it made me think how to help women like Dina to prioritise their health when they have always believed that they are subordinate to men. I felt sorry for Dina for being overly committed to her family and wider family, it is indeed exhausting to be always busy with housework and kids. I thought she was fully occupied by her family, close and wide, and had no time for friends she could talk to and relied on her family to provide her with information about her condition. This asserted to me that healthcare professionals need to provide women with proper education prolapse, but Dina already had lost trust in healthcare and has been avoiding them for four years. As a physiotherapist myself, I think it would take a lot of work to gain the trust of women like Dina who had been previously disadvantaged by healthcare. Part of physiotherapy treatment is to involve and actively engage the patient in the treatment plan even at home until she is seen in the next appointment. And the plan is adjusted in accordance to progress in the condition. If Dina was referred to physiotherapy with the trust issues she had towards healthcare, I assume she would not engage in the treatment and even would not attend treatment sessions.

## Lilly

Lilly was the third participant I interviewed. Around that time, my qualitative investigation skills were not much developed particularly in sense of engaging in depth with what Lilly was saying. Looking at the interview transcript, I wished if I asked her more exploratory question so she could elaborate or clarify furthermore. Lilly was willing to talk and share deep intimate details of her experience with prolapse. But there was a limitation in my behalf perhaps it was relevant to my skills or maybe there was a cultural barrier that was holding me back as there were times during the interview where I said to myself that it might be inappropriate for me to ask her to give more details, as I was bearing in my mind that this was a highly sensitive topic for her. I perhaps did not consider the fact that my role as a researcher was to bring her out of her comfort zone and reinforce her to talk more about her experience. But this was a beginner's mistake and was much improved in the following interviews.

My reality was different to Lilly's. What she told me about her overall experience seemed unusual to me, I knew there were a lot of women sharing my cultural background but in different levels. This was one of the interviews where I was able to capture the experiential claims but the reflection process was challenging due to our differences.

Lilly was my youngest participant. The age difference about us was around twenty years. Her eldest daughter was around my age when I interviewed her. When Lilly asked my about my marital status and said that I would not understand what she was about to say or would be less comfortable when saying it, this indeed was related to the cultural taboo of discussing sensitive issues with unmarried women

or women who never had sex. But it possibly could be that she felt that I was about her daughter's age and might have thought that it would not be appropriate.

#### Lujain

Lujain was the last participant I interviewed. She was happy to participate in my research and she provided me with deep information about her experience, despite her interview was relatively short. But some sensitive information was only disclosed after she asked about my marital status and knew that I was married.

Lujain was not the first participant to ask me if I was married or not so she could speak freely, but each time I was asked that question I wondered about the impact of my answer; either yes or no, on the response that I would get from my participant. And it also made me think about how comfortable women like Lujain feel while talking about their intimate problems to healthcare professionals and the level of freedom they allow themselves to have when talking about similar issues.

I am from a background that has always asserted that speaking about intimate issues is taboo, particularly to unmarried women or women who did not have sex in general. Despite being a women's health physiotherapist for almost a decade now and reading articles about sensitive topics, I still sometimes feel that it would be difficult for me too to talk about such issues because it is embedded in my culture, and this is what my brain have been subconsciously fed with. I can imagine how hard it must be for Lujain to talk about sex to unmarried healthcare professional as Lujain might feel that they do not understand what she is going through. I think a lot of work must be done in order to show women that they can speak to healthcare professionals about their sexual issues regardless of their marital status as they are qualified to help them.

The gender related ideologies that were present in Lujain's transcript, despite being fairly common in Saudi Arabia, they were at times disturbing for me to read. It was sad to see how the concept of male dominancy have adversely affected Lujain and her sisters, and I assume that there are many women out there, similar to Lujain and her sisters, are disadvantaged by it. I am aware that in the context of Saudi Arabia, the presence of men in women's life influence the decisions they make, and the way feel about themselves, and I thought that Lujain might not have sought

support or decided to have hysterectomy if her husband was not in the picture. Moreover, it was rare for me to see a sixty-year-old Saudi woman who was doing abdominal strengthening exercises, maybe she was controlling signs of aging and aiming to look younger for her husband. It will be challenging to convince women like Lujain that they have to look after themselves or manage prolapse for their own sake, not just for pleasing their husbands.

The analysis of Lujain's interview transcript was complex and emotional, looking at her experience and her narratives about her sisters' experiences and examining the ideas that were clearly shaped by culture about gender differences in terms of behaviours and roles and how they have accepted it, was sad. Lujain's husband did not seem one of those men who took advantage of the position they have socially acquired, but she was driven by her thought and beliefs. And perceiving herself to be blissful because her husband was fulfilling his roles as a man was also and evident of how she looked at herself, subordinate to men.

Lujain reflected a lot on the experience of her older sisters. I understand this because I also sometimes learn few things from my older sisters. But it was odd that she did not speak to them although she was willing to talk about her condition as she spoke to her mother. I assumed that she might not be close to her sisters to share such sensitive problems with them personally.

#### Mia

While reading Mai's interview over couple of times I could not help but to have judgmental thought like "she does not have any self-control". But I attempting to put my thoughts aside and closely engage with her narrative while trying to put myself in her shoes. And I felt sorry for Mai and other women that are living under similar gender ideologies and imbalanced family dynamics. I maybe sharing similar cultural background with Mai but my reality is fairly different than Mai's which could be attributed to factors like my social background and the opportunities I had in life. Hence, what Mai was saying in terms of her lack of agency in her personal choices in addition to her submissive role in family and marital relationship was unacceptable to me. But I know a lot of women like Mai, and after looking at her experience subjectively and engaging with her discourses, I somehow understand what it might be for women like Mai to experience prolapse in such social norms.

Mai spoke openly about her sex life and the things she has done to improve it and satisfy her husband. During the interview, I was able to engage with what she has been saying until she spoke about the sex being extreme and her husband asking her for anal sex. At this point I was captured by the social sensitivity of the topic. I felt an inner barrier that hindered me from probing further into the issue, and during the analysis, I ended up with many questions that I wished if I asked.

Mai mentioned being pregnant eight times and having episiotomy with each labour have caused her to be wide. But as a physiotherapist, I am aware that frequent childbirth and episiotomy increase the risk of developing prolapse through potential pelvic floor muscle trauma causing urinary incontinence and disturbing sexual function. This highlights the role of postnatal education and pelvic floor muscle assessment that can be provided by a women's health physiotherapist.

## Nabeela

Nabeela's reality was different than mine. She was entirely from an entirely different socioeconomic background; I think there was not so many things in common between us apart from our religious beliefs and the common laws and regulations in Saudi Arabia. Even her use of language was at times new to me but unfortunately a lot of these observations were lost during translation as a lot of differences were no longer there after translation. The process of translation was lengthy and difficult, finding the meaning of what she was saying in English language and capturing her background was at times impossible.

There are a lot of women like Nabeela whose realities are based upon the reality of their parents, I do not think that she had social connections or sisters and friends who she can speak to and hear about prolapse, rather she was connected to what her mother told her many years ago. I feel that effort should be made to educate women about prolapse and its risk factors rather than depending on similar familial experiences. Women also must be taught that healthcare is a better and more promising option when deciding to seek external support. I personally know a lot of women like Nabeela who prefer seeking traditional medicine for many healthcare problems despite lack of supporting evidence and consider it more useful that healthcare and modern medicine. And their justification is because this is what they have seen their mothers and grandmothers doing so it became like a proven traditional way to manage their conditions.

When Nabeela asked me whether she was going to have pessary placed or not on the day of the interview, I told her I did not know. She did not seem happy and sarcastically said that I should have known as I was doing a doctorate. Her response however to me not knowing her plan of management stunned me for a while, she was my first participant to interview and before her I had no interviewing experience . The right thing to say seemed to be telling her that I would be more prepared next time.

The way Nabeela made sense of pessary and how she spoke about it tells a lot about her personality. Her understanding was shaped by what the doctor told her. But I felt that women like Nabeela need to be treated cautiously as they might understand things they are told differently for various personal or contextual factors. This assert approaching each patient subjectively and bearing in mind where he or she are coming from and what would be the best way to deliver an information. I also had similar feelings when Nabeela spoke about the issue of being overweight and the fact that she was told repetitively to lose weight, I felt that her doctor was somehow insensitive when he told her about her increasing weight which she thought was out of her control.

## Salwa

Salwa was the only participant whose son was a physician. On the day she attended the hospital, her daughter was with her. She was a dentistry professor at the university. Before the interview when I was introducing myself to her and telling her about my research, her daughter noticed that my last name resembles one of her student's and then she knew that student was my sister. Salwa was there when her daughter was talking to me about my research and my sister who was her student. But during the interview as Salwa introduced herself as the mother of doctor (A) and telling me about her son who was also a physician at the university hospital, I felt that there has been minor power imbalance. I felt she might be expecting different response given her children are doctors at the hospital where she was being interviewed and maybe introducing herself like this has always given her some sort of status or unique treatment. This may have also been her way of expressing to me that there was a shared understanding between us.

Nevertheless, because of my assumptions, I faced barriers when interviewing Salwa as I felt that I had to be cautious while speaking to her. Indeed, after the interview I felt I did not engage with her very well but it also could be because she was not a talkative lady.

I was surprised that she decided to seek traditional medicine support, she said she was not convinced with the concept. I wondered about her children's response given their educational background, but this seemed to be enforced by women in her context and it is understandable how society sometimes force us to do things we do not agree with because others are doing it, maybe her children had no choice in this. Or maybe this is a signal that she was willing to try anything despite having an underlying belief in conventional medicine

Salwa said she knew nothing about prolapse and she did not ask her doctor about it and her doctor did not tell her much about her condition, I initially thought that Salwa was relying on her children to educate her about prolapse, but as the analysis was getting deeper this thought was rejected. But there was some level of knowledge in her narratives that was obtained from different resources.

Salwa has sought support of traditional medicine and healthcare, yet she was not referred to physiotherapy. Her children were healthcare professionals, and her son was a physician. Without considering the other possible factors why physiotherapy was not suggested, this scenario asserts the need for educating medical practitioners about the role of physiotherapy in managing prolapse. The guidelines followed in Saudi Arabia in terms of managing prolapse do indicate that pelvic floor muscle training improve the symptoms but does not state that it should be guided and supervised by a specialised women's health physiotherapist.

Contradiction in terms of knowledge was evident in Salwa's discourses possibly because information was gained from different resources. Improving women's health services is much needed, particularly, antenatal and postnatal services and including women's health physiotherapy is also valued. This is because education women about their pelvic floor muscles at this stage is critical, Salwa knew that it prolapse was relevant to childbirth but if she knew that she could protect herself from having it through antenatal and postnatal physiotherapy assessment and treatment programs around that time it would have been much useful to her. Moreover, this could have aided in resolving the issue of normalising prolapse as part of aging.

If there has been proper education, women like Salwa would not have relied on unauthorised resources to gain information about prolapse and how to manage it. it would have helped them to be in charge of their health and make informed decisions rather than depending on their friends and family.

Individualised pelvic floor muscle training program at early stages of prolapse has been proven to improve symptoms and muscle strength. Waiting for symptoms to get worse in order to seek help similar to Salwa will adversely affect the condition reaching the stage where conservative treatment will not work.

Prolapse is a sensitive condition, ineffective communication may give raise to fear and anxiety. And this was the case with Salwa, the doctor did not tell her much about her condition and she was left scared. Women must be approached subjectively while considering the biopsychosocial model and healthcare professionals obligations towards their patients and in order to deliver the right care.

#### Zainab

I think this interview was somehow shorter than the other interviews I had. Even the information provided here were straight forward and the analysis was less time consuming or complex, nevertheless, this was the sixth interviewed to be analysed so my assumption could be attributed to the possibility that my analytical skills are improving. Zainab spoke a lot about her experience with healthcare in the UK and in Saudi Arabia and her narratives highlighted the differences and the similarities between service provision in both countries and also in different sectors in Saudi Arabia.

I understood Zainab's struggle to find a specialised urogynecologist in Saudi Arabia because I know there are only few in Jeddah, but when she eventually did find one, I was happy because she found her experience to be blooming at a hospital that offers free services and accessible to women from different socioeconomic levels.

Her experience at the polyclinic and her feelings about it were not surprising to me, I do not have any judgement on private care in Saudi Arabia but what she said about the doctor wanting to see her a lot was understandable as there are some doctors who make profit by purposely delaying treatment or giving wrong management so the patient would visit them again and pay for the appointment and the treatment. But I don't think that this was the case with Zainab. Placing pessary requires specific training, it could be that the doctor was not trained. It also could be that the doctor was a gynaecologist who managed different conditions related to women but prolapse or pelvic floor dysfunctions are often managed by a urogynecologists. An as I mentioned above there are only few physicians with this subspeciality in Jeddah and they work in governmental hospitals. I thought that the doctor wanted to help her but could not.

In the UK, I was surprised that she was not offered to be referred to physiotherapy, but I think the doctor knew that Zainab was there temporarily, and physiotherapy would be inefficient as there would be no follow up to check progress.

Zainab's perception of herself as an old woman and what she was told in the UK was really interesting and showed the contrast in the culture's influence. I have women in my family who perceived themselves to be old as soon as they were fifty because their children were grown up, and their justification is that it is inappropriate for them to be seen acting young. Men on the other hand, are rarely seen behaving similar to women, in fact, a lot of men around that age consider seeking another younger wife because their wives start acting old.

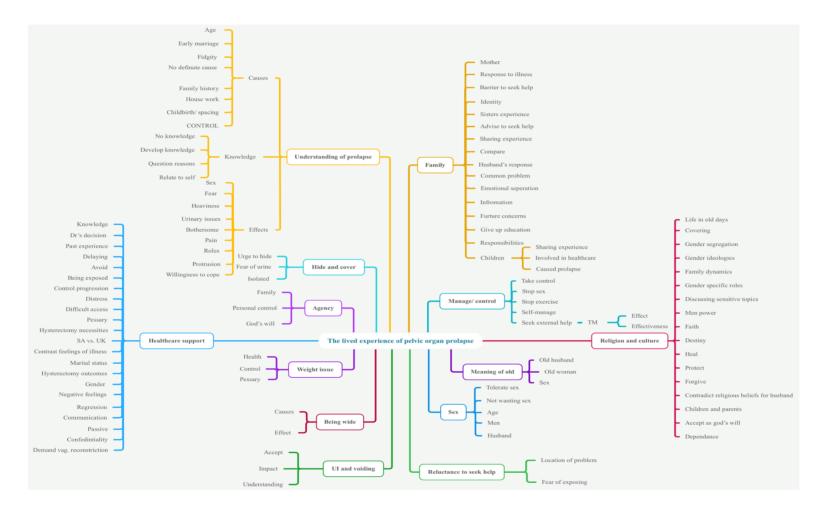
When Zainab's symptoms started, I thought she had willingness to seek help but waited until she was in the UK with her daughter. It occurred to me that she might be embarrassed to speak with any of her sons that she was having this problem given the sensitivity of the condition. Her son who was with her that day was a professor in the field of medical laboratory working at the university, yet I assume she did not speak to him about the problem she has otherwise she would not have waited to be with her daughter to seek help. This moved me to think about how the culture in Saudi Arabia may inform the experience of prolapse in terms of sharing the experience. This poses two different issues, the first one is the perception of the prolapse as taboo condition, the second one is depending on children to seek help, particularly sons.

The issue of prolapse being taboo could be lessened by educating women first about prolapse. In terms of dependence on children, women must be encouraged to be actively involved in their own health rather than depending on others. In case of Zainab, I think this could be because of her perception of herself as an old woman. She was with one of her children every time she sought support which could imply that she thought she required care, she was told about changing pessary by herself but she did not. The potential lack of willingness to be involved in treatment plan made me think about her response of she was seen by physiotherapy and was advised to carry on with home treatment plan and the efficiency of that.

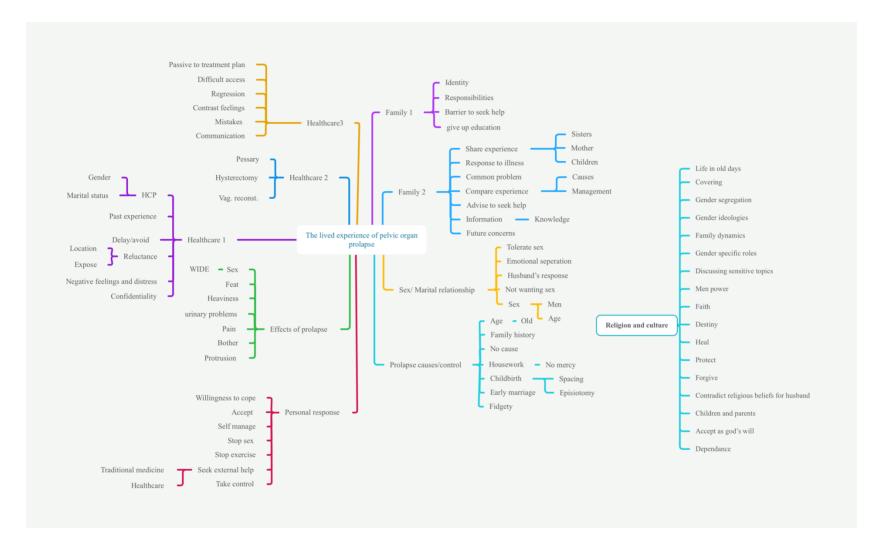
# Appendix I: The process of cross-case analysis

Themes\Part.	Aziza	Dina	Lilly	Lujain	Mai	Nabeela	Salwa	Zainab
Understanding of prolapse								
Causes and effects								
Family								
Sisters experience								
Reluctance to seek help								
Healthcare experience (SA)								
Hide and cover								
Taking control								
Cultural and religious perspectives								
Knowledge								

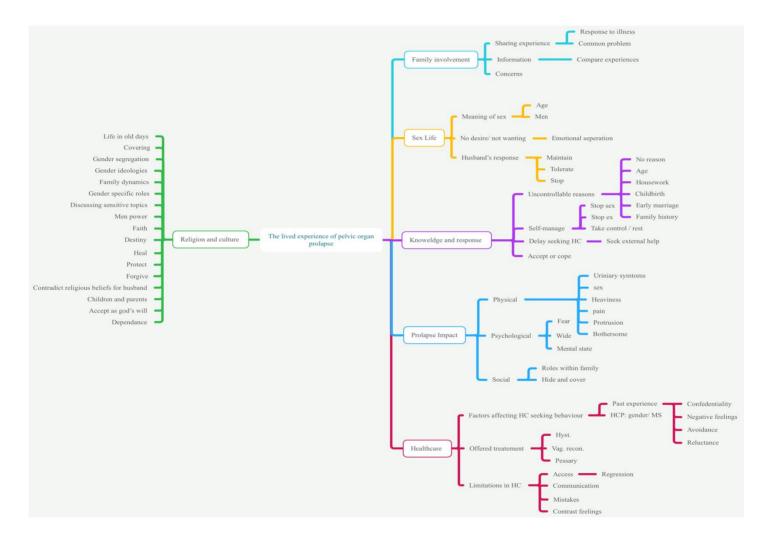
	1				
Urinary incontinence and voiding					
Being wide					
Self-manage					
Agency					
Mother					
Traditional medicine					
Weight issue					
The meaning of old					
Sex life					
Healthcare experience in UK					
Pessary					
Children					



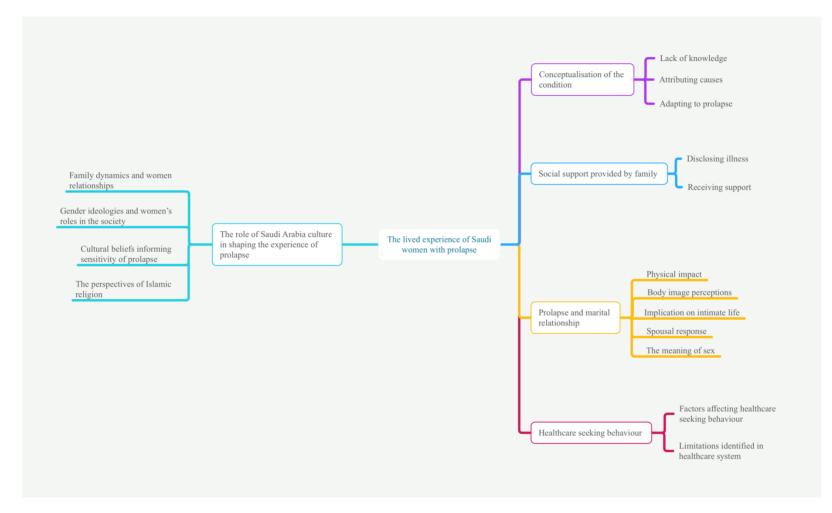
(Stage 1)



(Stage 2)



(Stage 3)



(Stage 4)

Theories	Relevance to study	Limitations
Holism	Acknowledges the importance of context in healthcare in addition to body, mind, spirituality, and emotional state. The experience of women with prolapse in Saudi Arabia did demonstrate impact of context in the way women experienced the condition. Hence, it further asserts providing care for women with prolapse in Saudi should be in holistic manners due to the complexity of the experience.	The themes generated from analysis both individual and group level demonstrated that the experience of prolapse is greatly informed by the culture in Saudi Arabia, I assume that using this theory will not show the great impact of culture rather it will discuss culture separate to the generated themes.
Culture care theory	<ul> <li>Holistic yet culture specific.</li> <li>Focus on culture, care, and health.</li> <li>Factors influencing care include religion, politics, economics, worldview, environment, cultural values, history, language, gender, and more.</li> <li>Nicely fits with my findings, culture basically shaped the experience of prolapse and it was evident in all the themes generated.</li> </ul>	Basically used by nurses but evidence suggest that findings of research adopting culture care theory extend beyond nursing and other health services. Ethnonursing* Funders issues **

# **Appendix J:** The choice between theoretical perspectives

	The ongoing societal changes in Saudi Arabia might be an indication that the experience of prolapse withing few years will be much different, HCP should consider the impact of changing culture on the experience and be open to this.	
Life-world	<ul> <li>Holistic.</li> <li>Have been used with many studies aiming to explore lived experience.</li> <li>Acknowledges understanding human experience to be important to improve quality of care.</li> <li>Any experience is part of a larger story, prolapse is not only experience of symptoms but it is experience of symptoms in a context. Here is discuss the important elements of the context in light of the experience. The elements are intertwined and relevant to my study.</li> <li>Shared and unique experiences are equally important.</li> </ul>	Concerned with meaning making, women in my study did not provide direct meaning except for sex. Only used in narrative and phenomenological studies, justifying the use of this theory might be problematic. Pure phenomenological background but resonates with my findings.

## **Appendix K: Study protocol**

## The experience of Saudi women with pelvic organ prolapse

## **Research question:**

What is it like for Saudi women at the age of menopause to experience the symptoms of pelvic organ prolapse?

## Aim of the study:

Explore the experience of premenopausal and menopausal Saudi women with pelvic organ prolapse in order to improve the delivery of women's health physiotherapy services.

## **Objectives:**

- Explore the impact of POP on Saudi women and their daily living activities.
- Does POP disturb the roles of affected women?
- Explore the impacts of POP on the intimacy of women and their relationship with spouse.
- Investigate how women manage the condition, and if they develop any coping strategy.
- Explore the views and perceptions of women in regard to what initially has caused the condition.
- Explore the healthcare seeking behaviour of Saudi women living with prolapse.
- Explore the influence of Saudi culture on the experience and healthcare seeking behaviour of women with POP.

## Methodological framework:

## **Research design:**

This study aims to explore the lived experience of women with prolapse and their healthcare seeking behaviour, hence, it seems that qualitative research design will sufficiently address the aims and objectives of the study. Qualitative research in healthcare sciences aims to establish a multidimensional understanding of an individual's experience of health-related condition that goes beyond our everyday assumptions; thus, leading to an informed and empathic practice (Kearney 2001).

## **Research approach:**

Interpretative phenomenological analysis (IPA) will be used as the methodological approach for this thesis to provide a structure for exploring the lived experiences of Saudi Arabian women with POP, together with their interpretations of the social world and how they make sense of their experiences.

## **Research methods:**

## Sampling:

IPA uses a small number of participants that are carefully situated and purposively selected as it offers the research project insight into a particular experience. Moreover, IPA is an idiographic approach that is concerned with understanding a particular phenomena in a particular context.

This study will explore the experience of 10 Saudi women with POP. Smith et al., (2009) suggest that three to six participants are reasonable sample size for an IPA study. Using a small sample size will develop meaningful points of similarities and differences between participants experiencing the phenomena of interest and will sufficiently address the aim of IPA approach., and the study objectives.

#### **Recruitment:**

Participants will be included in the study if they have the following criteria:

- Premenopausal and menopausal Saudi women.
- Women who did not undergo any surgical constructions to manage the condition.
- Speaking Arabic language and able to read and understand texts in Arabic.
- Women who do not suffer from any known mental health conditions.
- Women with no visual or speech impairment.
- Women with no physical disabilities.
- Women who have been sexually active at least in the last five years.

#### **Data collection method:**

IPA requires data collection method that enables collecting rich, detailed, first person account of experience. These requirements and preferences make in-depth one to one interview the best method to access such accounts. In-depth interviews "facilitate elicitation" of perceptions and thoughts about the phenomenon of interest while constantly focusing on person's experience, which makes it optimal for IPA studies.

## **Rigour:**

Rigour in IPA refers to the thoroughness of the study in terms of the appropriateness of sample to the research question, the quality of the interview and the completeness of the analysis undertaken. I will ensure that the samples are recruited carefully and reasonably homogenous in order to match research question. I will also ensure that I conduct a good quality interview that keeps balance between closeness and separateness, be consistent in one's probing, pick up important cues from participants and dig deeper. This might be challenging and demanding but I will manage to do so with proper supervision and training. In terms of rigour in analysis, I will ensure that there is sufficient idiographic engagement and the process is sufficiently interpretative.

# Appendix L: Data extraction table

Code	Author	Title	Place	Design	Methods	Sample		Findings
Body Image/ QoL	Jelovsek et al (2006)	Women seeking treatment for advanced POP have decreased body image and QoL	USA	Quantitative Case-control	Body image scale Short health form survey Generic QoL Pelvic floor distress inventory	Case:47 Grade: 3-4	Control:51 Grade: 0-1	Cases: more self-conscious about body Less physically attractive, feminine, sexually attractive (Sig low body image that moderately correlated with physical and mental QoL)
Body image	Lowder et al (2011)	Body image perception in women with POP; a qualitative study	USA	qualitative interviews	Structured focused groups	25 women Age (56-78) Stage 3 prol 7 focus grou (Grade 3 or	apse ps	<ul> <li>Body image: self-conscious</li> <li>Isolated</li> <li>Different</li> <li>Less attractive, desirable, feminin</li> <li>Disgust</li> <li>Body failing</li> <li>Handicap</li> <li>Sense of losing relationship</li> <li>Avoid intimacy</li> <li>Letting partner down</li> <li>Loss of interest in ADL</li> <li>Embarrassed</li> <li>Hopeful</li> <li>Can be fixed</li> </ul>

Experience/ healthcare seeking behaviour	Shrestha et al (2014)	Womens experience and healthcare seeking practices in relation to UP in a hill district of Nepal	Nepal	Mixed	In depth interviews Questionnaires	Questionnaire:107 Interview:16 (grade 3 or 4)	Physical discomfort: vaginal symptoms(85%), daily work and mobility, (68%) urinary incontinence, (42%) bowl symptoms, (71%) hold uterus during defecation. Sexual discomfort: (74%) discontinued sexual activities, painful Spouse behaviour: (16%) harassment threats to remarry or separate Domestic violence: (30%) excluded from social activities. Self-perceived reasons: Repeated pregnancies, heavy work at postnatal period Healthcare seeking: (48%)shame, (12%) not necessary, stigma, normal to childbearing, seek healthcare for UI
Experience/ QoL	Srikrishna et al (2008)	Experience and expectations of women with urogenital prolapse: a quantitative and qualitative study	UK	Mixed	Semi structured interviews Prolapse quality of life questionnaire	43 women with POP Mean age 56 Prolapse grade: 2 or more	pQoL not reflective of: general health judgement, role limitation, physical and social activity, sexual function. Reflective of: emotions and energy, symptoms, psychological factor.

Sexual health	Ozengin et al (2017)	The effect of pelvic organ prolapse type on sexual function, muscle strength, and pelvic floor symptoms in women: a retrospective study	Turkey	Retrospective cohort Quantitative	Pelvic organ prolapse quantification Vaginal pressure measurement Pelvic organ prolapse/urinary incontenenece sexual questionnaire 12 Pelvic floor distress inventory-20	Case : Ant prolapse : 96 Apical prolapse : 20 Post prolapse : 16 (Grade 2 or more)	Control : 36 (asymptom atic grade 1)	Prolapse does not correlate with sexual dysfunction
Sexual health	Roos et al (2014)	Pelvic floor dysfunction: women's sexual concerns revealed	Netherla nds	Qualitative	Semi structured interviews	36 women p undergo surg POP: 17 UI: 8 POP/ UI: 11 Age: 31-64	gery	Body image: POP "Ugly, not normal, big, loose" embarassement, depressed, low confidence, not attractive, concerned with partner's experience, old Sexual desire: POP; no motivation, fear of pain, discomfort, difficulties with penetration, insecurity, damage prolapse, reduced sensation, unsatisfactory. Arousal: POP; difficult, mentally distracted, not normal Orgasm: POP; reduced sensation, difficult, less intense Dyspareunia: Only with POP; discomfort, obstruction, avoid some positions.

healthcare seeking behaviour	Pakbaz et al (2011)	Vaginal prolapse- perception and healthcare seeking behaviour among women prior to gynaecological surgery	Sweden	Quantitative Prospective cross sectional	Developed questionnaire	Cases: 214	Control: Non malignant hysterecto my: 186 UI: 161	POP interferes with sexual activity Women with prolapse don't think it is a trouble that needs intervention One of each five women with POP did not know that prolapse symptoms are actually caused by prolapse Women with prolapse have fewer sourced of information compared to other groups
QoL	Sami et al (2015)	QoL among women with symptoms of gynaecological morbidities: results of a cross sectional study in karachi, Pakistan	Pakistan	Quantitative Cross sectional	HRQoL	Women age:	15-49	Prevalence of gynecologocal disorders: 57% Vaginal prolapse most reported to affect QoL physically, functionally and financially

Experience	Gjerde et al (2016)	Living with POP: voices of women from Amhara region, Ethiopia	Ethiopia	Qualitative	In depth interviews	24 women with POP (grade 2 and more) Mean age: 40	Conceptualizing the condition: childbirth causes prolapse, no rest during or after pregnancy, heavy workload, God's will or anger, bad eye Daily life challenges: water fetching problems, no rest, difficulty walking and sitting and urination, social roles impaired. Sexual implication: most are active "this is marriage", sleep alone, lie to spouse to avoid intercourse, separation. Managing the condition: continue living their lives doing their daily work, take rest in between, sit on folded clothes, push uterus n when urinating, rub with oil to moisten Disclosure: shameful, ignored, disgusting, no solution, discrimination, worry and pain, insults
QoL	Digesu et al (2005)	The relationship of vaginal prolapse severity to symptoms and QoL	UK	quantitative cross-sectional	Self administered POP-Q and P-QoL	355 women: POP: 233, mean age: 57 Control: 122, mean age:48	POP-Q and P-QoL scores significantly higher in women with POP. P-QoL scores increase with increased prolapse stage (correlation) Anterior POP: urinary symptoms Posterior POP: bowl symptoms Apical: sexual symptoms

Sexual health	Athanasiou et al (2012)	Pelvic organ prolapse contributes to sexual dysfunction: a cross sectional study	Greece	Qunatitative Cross- sectional	POP-Q Sexual dysfunction questionnaire DYSQ	Case : 69 Mean age : 48 Symptoma tic POP (grade 1-4)	Control : 61 Mean age : 44	Both groups equally sexually active : POP less desire, satisfaction. POP: only 49% achieve orgasm, coital incontinence Grade of POP doesn't correlate with its sexual dysfunction
Healthcare seeking behaviour	Hammad et al (2018)	The degree of bother and healthcare seeking behaviour in women with symptoms of POP from a developing gulf country	Emirates	Quantitative Cross- sectional	Self developed questionnaire	482 women: reported syn POP Mean age: 3	ptoms of	POP affected physical and social activities in addition to praying and sexual relationship (mild to severe) 69 women did not seek healthcare: shyness, male practitioner, lack of knowledge, unaware of existing treatment Healthcare seeking behaviour affected by: the need to insert finger to empty bowl and bladder, and physical activity restriction

QoL	Sahin et al (2015)	Assessment of the quality of life in women with a diagnosis of urogenital prolapse	Turkey	Quantitative	Self developed questionnaire in accordance with literature and prolapse life quality scale	179 women diagnosed with POP Mean age: 52	<ul> <li>77% did not consult hospital</li> <li>57% 3rd grade prolapse</li> <li>43% consulted hospital due to</li> <li>incontinence not prolapse</li> <li>60.9% difficulty urination and</li> <li>defecation</li> <li>-non significant impact on QoL: QoL</li> <li>only impacted with increased degree</li> <li>of prolapse (grade 3 or more)</li> </ul>
Experience	Roets, L (2007)	The experience of women with genital prolapse	South Africa	Qualitative	Phenomenology in depth interviews	19 women with POP Age: 48-77 Grade1: 8 Grade 2: 8 Grade 3: 3	Emotional expperience : shame (6 participants)/ Anxiety (due to UI)/ Despondency/ Unpleasent (due to UI) Self-esteem: Self image (grade 1-2) Social interaction: Social activities (grade 3 activities were not limited at all) Toilet habits: 73% had UI Physical discomfort: LBP/ Discomfort No knowledge regarding POP
Body image/ Sexual health	Zielinski et al (2009)	Body image and sexuality in women with POP	USA	Mixed	Vaginal changes sexual and body esteem scale Semi-structured interviews	13 women with POP Age: 33-81	Scores of VSBE: sexually active women < non sixually active women Prolapse severity and body-esteem: no correlation Qualitative: UI affect body image and sexuality/ prolapse cause discomfort during intercourse/ some women are concerned with partneres response/

							prolapse changes how women feel about their femininity
Healthcare seeking behaviour	Pakbaz et al (2010)	A hiddin disorder until the pieces fall into place' - a qualitative study of vaginal prolapse	Sweden	Qualitative	In depth interviews	14 women with POP prior to surgery / Age: 42-79	Obstacles: Absence of information/ blaming oneself/ ignored by doctor/ covert condition/ de-prioritizing own health Facilitators: support by others/ difficulty accepting aging body/ sexually unattractive/ unnatural body reaching point of action
Knowledge and attitude of uterus	Good et al (2013)	Prolapse-related knowledge and attitudes toward the uterus in women with pelvic organ prolapse symptoms	USA	Quantitative Cross- sectional	Self developed questionnaire	213 only english speaking women/ no past hysterctomy/ age:58±14	Limited knowledge about prolapse and management options/ uterus not percieved relevant to femininty + not necessery for sexual function
knowledge profeciency	Mandimika et al (2014)	Knowledge of pelvic floor disorders in a population of	USA	Cross sectional survey	unmodified Prolapse and Incontinence Knowledge Questionnaire (PIKQ)	431 racially and socioeconomically	71.2% of subjects lacked UI proficiency/ 48.1% lacked proficiency in POP knowledge/ deficits in knowledge about UI and

		community- dwelling women				diverse women aged 19- 98 years.	POP in women of all ages, races, and socio- economic levels.
Experience	Dunevan et al (2014)	Pelvic Organ Prolapse: A Disease of Silence and Shame	USA	Qualitative (GT)	Deep interviews	8 focus groups/ 4 english and 4 spanish	lack of knowledge, feelings of shame regarding their condition, difficulty in talking with others, fear related to symptoms, and emotional stress from coping with pelvic organ prolapse. In addition, Spanish speaking women included fear related to surgery and communication concerns regarding the use of interpreters. Two overarching concepts emerged: first - a lack of knowledge which resulted in shame and fear; and second - public awareness regarding pelvic organ prolapse is needed. From the Spanish speaking an additional concept was the need to address language barriers and the use of interpreters.
Sexual function	Barber et al (2002)	Sexual Function in Women With Urinary Incontinence and Pelvic Organ Prolapse	USA	Quantitative (secondary analysis)	questionnaire	343 women older than 45 years with urinary incontinence or prolapse: 316 UI-32 POP	One third of patients with prolapse reported that their pelvic floor condition affected their ability to have sexual relations "moderately" or "greatly" significantly more than did other groups/ Prolapse is more likely than urinary incontinence to result in sexual inactivity and to be

							perceived as affecting sexual relations.
Sexual experience	Hadizadeh- Talasaz et al (2019)	Exploration of sexual experience among women with pelvic organ prolapse: a qualitative study	Iran	Qualitative content analysis	Deep interviews	20 women with symptomatic prolapse aged 44±10	Experience of sexual discomfort All women with POP stated that they have had experiences of discomfort with sex/ Damaged genital body image: "ugly," "smelly," "not normal," "dirty," and "loose, feel less femininity/ Psychological problem: range of negative emotional responses in their everyday life including, depression, fear, anxiety, embarrassment, and anger./ Husband's response to prolapse: Men responded differently to their women's problem and ranged from indifferent to supportive./ Sexual problem management: avoided certain sexual positions, limit fluids, humor

Experience/ QoL	Brandt and vuuren (2019)	Dysfunction, activity limitations, participation restriction and contextual factors in South African women with pelvic organ prolapse	South Africa	quantitative	Prolapse-Quality of Life (P-QOL) questionnaire and the Visual Faces Scale.	100 women mean age 59	Eighty-six per cent had a stage III POP, 57% had overactive bladder, 50% had constipation, 37% had stress urinary incontinence, 31% had urge urinary incontinence, 32% had incomplete emptying and 30% had anal incontinence. Comorbidities included cardiovascular disease (65%), depressive symptoms (12%) and hypothyroidism (18%). Other contextual factors included limited physical activity (80%), an increased body mass index (29 kg/m2), older age (59 years) and unemployment (80%). Quality of life was affected in the severity, social, emotional and sleep/energy domains. domains that included physical activity as a limitation (namely the domains of role and physical limitations) were less impaired by the prolapse. Personal relationships were least affected
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