

**COUPLES' EXPERIENCES OF PROSTATE  
CANCER TREATMENT IN MALTA: A  
DESCRIPTIVE QUALITATIVE  
INVESTIGATION**

Gerrit Albertus van Dijk

A thesis submitted in partial fulfilment of the requirements for Cardiff  
University for the degree of Doctor of Philosophy

2022

## **SUMMARY**

### **Background**

Prostate cancer treatment can negatively impact the functioning of men in several domains, including urinary, sexual and social functioning, this may influence couples' lives and relationships. Couples need to adjust to the changes caused by prostate cancer and may face considerable distress and issues along the way. This current study investigated the experiences of couples up to two years following external beam radiotherapy treatment in Malta.

### **Research aims and objectives**

The aim of this research was to explore the experiences of men (aged 64-74 years) and their partners in the first two years following external beam radiotherapy treatment for prostate cancer in Malta.

The objectives of this study were to explore:

- Experiences of the healthcare system for men and their spouses before commencing external beam radiotherapy treatment.
- Experiences of undergoing external beam radiotherapy treatment for prostate cancer for men and their spouses.
- Men and their spouses' experiences of the follow-up care after the completion of external beam radiotherapy treatment for prostate cancer.
- The impact of an external beam radiotherapy treatment for prostate cancer on the lives and relationships of men and their spouses.

## Summary

### **Methodology and methods**

This study employed a qualitative descriptive methodology and data were collected via in-depth interviews with twelve couples and two men who underwent prostate radiotherapy treatment. The data were analysed thematically using Braun and Clarke's (2006) method of analysis, which incorporated familiarisation, generation of initial codes, searching for themes, reviewing themes and defining and naming of themes.

### **Findings**

A diagnosis and treatment for prostate cancer was found to be a significant source of anxiety and distress for couples. Several areas were identified that were of particular concern, these included the following: the treatment decision-making process after diagnosis, bladder filling procedures during radiotherapy and follow-up arrangements after treatment. Findings revealed that some couples appraised the illness as a shared concern and other men adopted a more individual approach. It is proposed that the approach adopted by the men and their spouses had a strong link to the Developmental Contextual Model (DCM) of coping with stress.

### **Conclusion**

Through the use of a qualitative descriptive approach, this study revealed the challenges that couples may face when living with prostate cancer, but also the abilities of some couples to integrate and adjust these changes into everyday life.

## **ACKNOWLEDGMENTS**

My sincerest thanks go to the twelve couples and two men, who gave their time to share their experiences and stories with me. Without their help and assistance this study would not have been possible.

I would also like to express my sincere gratitude to my supervisor, Dr Paul Gill, for his continuous support, advice and guidance over the past years. Your words of encouragement were instrumental in motivating me throughout this PhD study and the writing of this thesis. Similarly, I would like to thank the other members of the supervisory team, Dr Paul Brown and Dr Paul Bezzina, who have always been there to inspire me with their insightful advice, support and guidance throughout this study. Additionally, I would also like to thank Dr Nicholas Courtier for his support and guidance during the final write-up stages of this study. I would also like to thank Ms Stephanie Cutajar for reading this thesis and providing useful suggestions and corrections.

I would like to thank all my friends, including colleagues at the University of Malta, from which I have found much support and encouragement over the years. I sincerely appreciate all the times you were there and had to put up with my ups and downs of this PhD study. I gratefully acknowledge the funding received towards my PhD from the University of Malta.

Above all, I would like to thank my wife Bernice as without your support, belief and patience, this would not have been possible. Together with Tim and Nick, you have been there to brighten up my days and have helped me to persist throughout the challenges and difficult moments encountered during this research study. No words could describe how grateful I am with having you all in my life.



## TABLE OF CONTENTS

<b>Summary</b> .....	<b>ii</b>
<b>Acknowledgments</b> .....	<b>iv</b>
<b>Table of contents</b> .....	<b>v</b>
<b>List of tables</b> .....	<b>xii</b>
<b>List of figures</b> .....	<b>xiv</b>
<b>List of acronyms and abbreviations</b> .....	<b>xv</b>
<b>Chapter 1. Introduction</b> .....	<b>1</b>
1.1. Introduction .....	1
1.2. Motivation for study .....	1
1.3. Research question and objectives .....	2
1.4. Thesis overview .....	3
1.5. Conclusion .....	4
<b>Chapter 2. Scene setting</b> .....	<b>5</b>
2.1. Introduction .....	5
2.2. Cancer .....	5
2.3. Cancer in Malta .....	6
2.4. Prostate cancer .....	7
2.5. Prostate cancer classification.....	7
2.6. Prostate cancer treatment.....	9
2.6.1. <i>Radical Prostatectomy</i> .....	10
2.6.2. <i>External Beam Radiotherapy</i> .....	10
2.6.3. <i>Brachytherapy</i> .....	11
2.6.4. <i>Hormonal treatment</i> .....	11

## Table of contents

2.6.5. <i>Combination of treatments</i> .....	12
2.7. Impact of prostate cancer treatment on female spouses.....	12
2.8. Health policies and cultural background.....	13
2.8.1. <i>European health policies</i> .....	14
2.8.2. <i>The Maltese National Cancer Plan</i> .....	15
2.8.3. <i>Cultural background</i> .....	16
2.9. Conclusion .....	18
<b>Chapter 3. Literature Review .....</b>	<b>19</b>
3.1. Introduction .....	19
3.2. Literature search strategy .....	19
3.3. Synthesis of the literature.....	22
3.3.1. <i>Quality-of-life changes over time</i> .....	24
3.3.2. <i>Age-specific considerations</i> .....	25
3.3.3. <i>Treatment-specific considerations</i> .....	25
3.3.4. <i>Impact of prostate cancer treatment on couples' lives and relationships</i> .....	26
3.4. Quality-of-life changes of couples over time .....	26
3.4.1. <i>Quality-of-life changes over time</i> .....	27
3.5. Age-specific considerations .....	33
3.5.1. <i>Development life stage and prostate cancer</i> .....	34
3.6. Treatment-specific considerations.....	37
3.6.1. <i>Impact of treatment option on couples' experiences</i> .....	37
3.7. Impact of a prostate cancer treatment on the life and relationship of couples .....	42
3.7.1. <i>Sexual changes following prostate cancer treatment</i> .....	43

## Table of contents

3.7.2. <i>Couples' psychosocial needs during and after prostate cancer treatment</i> .....	47
3.7.3. <i>Coping with prostate cancer as a couple</i> .....	49
3.8.    Summary.....	53
3.9.    Conclusion .....	54
<b>Chapter 4. Methodology</b> .....	<b>55</b>
4.1.    Introduction .....	55
4.2.    Research aim and questions.....	55
4.3.    Philosophical Assumptions .....	56
4.4.    Study Design.....	58
4.5.    Qualitative descriptive methodology.....	59
4.6.    Choosing a qualitative descriptive methodology .....	61
4.7.    Methods for data generation .....	63
4.7.1. <i>Negotiating access and participants recruitment</i> .....	63
4.7.2. <i>Recruitment and sampling</i> .....	64
4.7.3. <i>Data generation methods: in-depth interviews</i> .....	68
4.7.4. <i>Managing the interviews</i> .....	79
4.7.5. <i>Pilot interviews</i> .....	80
4.8.    Methods of data analysis .....	82
4.8.1. <i>Inductive or deductive approach</i> .....	82
4.8.2. <i>Explicit / interpretive level</i> .....	83
4.8.3. <i>Thematic Analysis</i> .....	83
4.8.4. <i>Computer assisted qualitative data analysis software</i> .....	92
4.9.    Ethical and governance considerations.....	93
4.9.1. <i>Respect for autonomy and informed consent</i> .....	94

## Table of contents

4.9.2.	<i>Anonymity and Confidentiality</i> .....	95
4.9.3.	<i>Confidentiality</i> .....	97
4.9.4.	<i>Minimising risk and harm to participants</i> .....	98
4.10.	Trustworthiness .....	99
4.10.1.	<i>Credibility</i> .....	100
4.10.2.	<i>Transferability</i> .....	101
4.10.3.	<i>Confirmability</i> .....	102
4.10.4.	<i>Dependability</i> .....	103
4.11.	Reflexivity statement.....	103
4.11.1.	<i>Personal and professional characteristics</i> .....	104
4.11.2.	<i>Insider/outside research</i> .....	104
4.11.3.	<i>Language</i> .....	106
4.12.	Conclusion .....	107
<b>Chapter 5. Findings .....</b>		<b>108</b>
5.1.	Introduction .....	108
5.2.	Theme 1 – Getting to grips with prostate cancer.....	113
5.2.1.	<i>Introduction</i> .....	113
5.2.2.	<i>Initial signs and symptoms</i> .....	117
5.2.3.	<i>Treatment or examination delays</i> .....	118
5.2.4.	<i>Disclosing the diagnosis to others</i> .....	120
5.2.5.	<i>Making a management decision</i> .....	123
5.3.	Theme 2 - Navigating the prostate cancer treatment pathway... .....	127
5.3.1.	<i>Introduction</i> .....	127
5.3.2.	<i>Radiotherapy treatment experiences</i> .....	131

## Table of contents

5.3.3.	<i>Radiotherapy side effects</i> .....	135
5.3.4.	<i>Hormone specific side effects</i> .....	137
5.3.5.	<i>Psychosexual consequences</i> .....	138
5.3.6.	<i>Body image / Masculinity concerns</i> .....	139
5.3.7.	<i>Psychological Impact</i> .....	141
5.4.	Theme 3 – Dealing with changing health status.....	143
5.4.1.	<i>Introduction</i> .....	143
5.4.2.	<i>Dealing with prostate cancer alone</i> .....	146
5.4.3.	<i>Minimizing impact and hiding emotions</i> .....	147
5.4.4.	<i>Changes related to age</i> .....	148
5.5.	Theme 4 – Balancing different spousal roles .....	150
5.5.1.	<i>Introduction</i> .....	150
5.5.2.	<i>Not involved or side lined</i> .....	154
5.5.3.	<i>Supporting their husbands</i> .....	155
5.5.4.	<i>Emotional impact on spouses</i> .....	156
5.5.5.	<i>Setting personal feelings aside</i> .....	158
5.6.	Theme 5 - Reframing the relationship.....	159
5.6.1.	<i>Introduction</i> .....	159
5.6.2.	<i>Communication</i> .....	163
5.6.3.	<i>Couples’ coping strategies</i> .....	164
5.6.4.	<i>Comparing and contrasting</i> .....	168
5.6.5.	<i>Couples’ supportive care needs</i> .....	169
5.7.	Conclusion .....	172
	<b>Chapter 6. Discussion</b> .....	<b>173</b>
6.1.	Introduction .....	173

## Table of contents

6.2. Emotional impact of a prostate cancer diagnosis and treatment on couples .....	175
6.2.1. <i>Pre-treatment communications with healthcare professionals</i> .....	176
6.2.2. <i>Bladder filling during radiotherapy treatment</i> .....	186
6.2.3. <i>Post-treatment impact of prostate cancer treatment on couples</i> .....	191
6.3. A shared or individual approach to dealing with prostate cancer .....	199
6.3.1. <i>Cancer-related communication patterns</i> .....	200
6.3.2. <i>Gender and role expectations when dealing with prostate cancer</i> .....	205
6.3.3. <i>Social and cultural influence of couples dealing with prostate cancer in Malta</i> .....	213
6.4. Couples coping with stress .....	218
6.4.1. <i>Models of dyadic coping</i> .....	218
6.4.2. <i>Development Contextual Model (DCM)</i> .....	223
6.4.3. <i>Application of DCM model to my study</i> .....	225
6.4.4. <i>Theoretical frameworks used in other studies and implication of DCM model on healthcare professional</i> .....	233
6.5. Conclusion .....	238
<b>Chapter 7. Conclusions and recommendations</b> .....	<b>240</b>
7.1. Introduction .....	240
7.2. Review of research question and objectives .....	240
7.3. Original contribution to knowledge .....	241

Table of contents

7.4. Publication and dissemination strategy.....	247
7.5. Study limitations .....	249
7.6. Recommendations .....	250
7.6.1. <i>Clinical practice recommendations</i> .....	250
7.6.2. <i>Future research</i> .....	253
7.7. Chapter conclusion .....	254
<b>References .....</b>	<b>256</b>
<b>Appendix one – Literature review and synthesis of the literature .....</b>	<b>295</b>
<b>Appendix two – Ethical approval documentation .....</b>	<b>356</b>
<b>Appendix three – Consent forms.....</b>	<b>398</b>
<b>Appendix four – Data Analysis .....</b>	<b>399</b>
<b>Appendix five– Researcher diary .....</b>	<b>412</b>

## LIST OF TABLES

Table 1: EAU risk groups for biochemical recurrence of localised and locally advanced prostate cancer (Mottet et al. 2021) .....	8
Table 2: Interview questions and examples of follow up questions..	71
Table 3: An example of the development of code into candidate theme .....	88
Table 4: Participant characteristics of couple interviews .....	109
Table 5: Overview of theme 1 – Getting to grips with prostate cancer including subthemes, codes and nodes created from Nvivo and excerpt examples .....	114
Table 6: Overview Theme 2 – Going through the prostate cancer journey including subthemes, codes and nodes created from Nvivo and excerpt examples. ....	128
Table 7: Overview Theme 3 – Dealing with changing health status including subthemes, codes and nodes created from Nvivo and excerpt examples .....	144
Table 8: Overview Theme 4 – Balancing different spousal roles including subthemes, codes and nodes created from Nvivo and excerpt examples .....	151



List of tables

Table 9: Overview Theme 5 – Reframing the relationship theme including subthemes, codes and nodes created from Nvivo and excerpt examples .....160

Table 10: *Characteristics of hegemonic masculinity (Connell and Messerschmidt 2005)* .....207

Table 11: Action plan to publish and disseminate findings .....248

## LIST OF FIGURES

Figure 1: Projected annual increase in the number of new cancer per year up to 2030 (Malta National Cancer Registry 2016).....	6
Figure 2: Identification and screening of literature articles .....	22
Figure 3: Matrix coding query for codes specific to males .....	89
Figure 4: Matrix coding query for codes specific to females .....	90
Figure 5: Matrix coding query for male and female .....	90
Figure 6: Diagram depicting the different themes according to the treatment stage and relationship with each other .....	112
Figure 7: Dyadic appraisal, coping and adjustment (Berg and Upchurch, 2007).....	224

## **LIST OF ACRONYMS AND ABBREVIATIONS**

ADT	Androgen Deprivation Therapy
DCM	Developmental Contextual Model
EAU	European Association of Urology
GS	Gleason Score
GI	Gastrointestinal
GU	Genitourinary
HDR	High Dose Rate
IARC	International Agency for Research on Cancer
IGRT	Image-guided radiotherapy
IMRT	Intensity-Modulated radiotherapy
ISUP	International Society for Urological Pathology
LAPCD	Life After Prostate Cancer Diagnosis
LDR	Low dose rate
LHRH	Luteinizing-hormone releasing hormone
PSA	Prostate-specific antigen
QoL	Quality of Life
REC	Research Ethics Committee
RP	Radical Prostatectomy
TNM	Tumour Node Metastasis staging system
VMAT	Volumetric Modulated Arc Therapy
WHO	World Health Organisation
3D-CRT	Three-dimensional conformal radiotherapy

## **CHAPTER 1. INTRODUCTION**

### **1.1. INTRODUCTION**

Prostate cancer is the most commonly diagnosed cancer in men in Europe (Ferlay et al. 2021). Treatment options for prostate cancer are associated with excellent survival rates. The various treatment options available for prostate cancer are often considered to be equally effective in terms of survival, however each treatment option may have different treatment related long-term consequences. These consequences may impact on several areas, including physical and sexual functioning which could negatively impact men and their partners (Collaco et al. 2018). External beam radiotherapy treatment is a common treatment approach for prostate cancer and this current study considers the experiences of men and their partners in the first two years following this treatment option. This first chapter considers my personal motivation for undertaking the study, outlines the research questions and objectives, and provides an overview of the thesis.

### **1.2. MOTIVATION FOR STUDY**

My professional role in the academic and clinical education of undergraduate students has provided me with opportunities to observe how students and staff go about their practice within the local oncology hospital. Particular observations of the radiotherapy and outpatient follow-up clinic, and my subsequent reflections about such observations, have contributed to my personal interest in this area.

It was noted that men undergoing prostate cancer treatment were often accompanied by their partners when they attended specialist led clinics. Another incident that particularly triggered my interest in this

## Introduction

study was a patient panel session that was conducted in 2015. A patient panel session was organised as part of the BSc. Radiography course with the final year students. The aim of this session was to explore issues from a patient's perspective in order to inform and improve care. For this session, three men who underwent prostate cancer treatment were recruited and two partners joined the session. The participants of this patient panel highlighted several areas that they felt could be improved, such as the involvement of their partners in the care process. I felt that further research in this area could be beneficial in order to explore couples' experiences and identify areas that may be targeted for future interventions.

European reports and the local national cancer plan suggest that cancer services should be patient-centred and take account of the views and preferences of patients and families (Ministry for Health [Malta] 2017; European Union 2021; Mottet et al. 2021). I felt that there was a need to investigate this in the local oncology hospital, where little related research had been conducted.

### **1.3. RESEARCH QUESTION AND OBJECTIVES**

The aim of this research was to explore the experiences of men (aged 64-74 years) and their partners in the first two years following external beam radiotherapy treatment for prostate cancer in Malta. The main research question for this study was:

- *What are the experiences of men (aged 64-74 years) and their partners in the first two years following external beam radiotherapy treatment for prostate cancer in Malta?*

The objectives of this study were to explore:

- Experiences of the healthcare system for men and their spouses before commencing external beam radiotherapy treatment.

## Introduction

- Experiences of undergoing external beam radiotherapy treatment for prostate cancer for men and their spouses.
- Men and their spouses' experiences of the follow-up care after the completion of external beam radiotherapy treatment for prostate cancer.
- The impact of an external beam radiotherapy treatment for prostate cancer on the life and relationships of men and their spouses.

### **1.4. THESIS OVERVIEW**

This thesis is organised into a further six chapters. Chapter two provides an overview of prostate cancer treatment from an international and Maltese perspective. The different treatment options are introduced, and an overview of the local health policies is provided. Finally, chapter two presents the impact of treatment on men and their partners.

Chapter three presents the literature search strategy and critical review and synthesis of the literature. This chapter examines the impact of prostate cancer on the quality of life (QoL) of couples over time and includes quantitative and longitudinal studies. This is followed by an examination of the impact in relation to the age of men at diagnosis and the impact of specific treatment options on couples. The final part of this chapter examines qualitative studies which include feedback from couples in order to provide further context for this study.

Chapter four presents the qualitative descriptive methodology chosen for this study. The use of dyadic interviews is further presented in this chapter and the collection and analysis of data is introduced. Finally, this chapter discusses some of the ethical issues, including informed consent and confidentiality, involved in the research.

## Introduction

Chapter five presents the findings of this study, it considers participants' pre-treatment experiences, where couples discuss their initial experiences associated with the prostate cancer diagnosis, their involvement in the treatment-decision process and the ways in which couples adjusted to their new situation. This is followed by their experience of undergoing prostate cancer radiotherapy treatment and the associated side effects. The final section presents the impact of prostate cancer treatment on men, their partners and on couples' relationships.

Chapter six discusses the findings within the wider context of the relevant prostate cancer and couples' coping literature, clinical guidelines and health policies. Finally, a theoretical framework is proposed that informs how couples cope and adjust to prostate cancer.

Chapter seven concludes this thesis; it outlines the contribution to knowledge of this study and presents recommendations for clinical practice and future related research.

## **1.5. CONCLUSION**

This chapter has provided a broad overview of this current study. The next chapter provides an overview of prostate cancer and sets the scene for the study.

## **CHAPTER 2. SCENE SETTING**

### **2.1. INTRODUCTION**

This chapter provides the context of this research by presenting an overview of the general cancer burden, which subsequently focuses on prostate cancer. The first section considers the development of prostate cancer, common treatment options and the potential impact on men and their spouses. The second section provides an overview of the local Maltese health policies and socio-cultural setting within which this study takes place.

### **2.2. CANCER**

It has been estimated that one in five men and one in six women worldwide develop cancer during their lifetime, and one in eight men and one in 11 women die from the disease (Bray et al. 2018). Cancer is a major cause of morbidity and mortality, with an estimated 19.3 million new cases of cancer and 10 million cancer deaths occurring in 2020 worldwide (Sung et al. 2021).

In Europe the leading cancer amongst women is breast cancer. This is also the leading overall cause of death from cancer in women (Ferlay et al. 2021). For men, prostate cancer has emerged as the most common cancer in Europe following a rapid increase in the detection of a substantial number of early-stage prostate cancers, during the early to mid-1990s, across the higher income countries of Northern, Western and Southern Europe (Ferlay et al. 2021). Although prostate cancer is the most commonly diagnosed cancer in men in Europe, prostate cancer survival has improved over the last several decades in many countries, with five-year survival rates now more than 90% in most parts of Europe (Marhold et al. 2022).

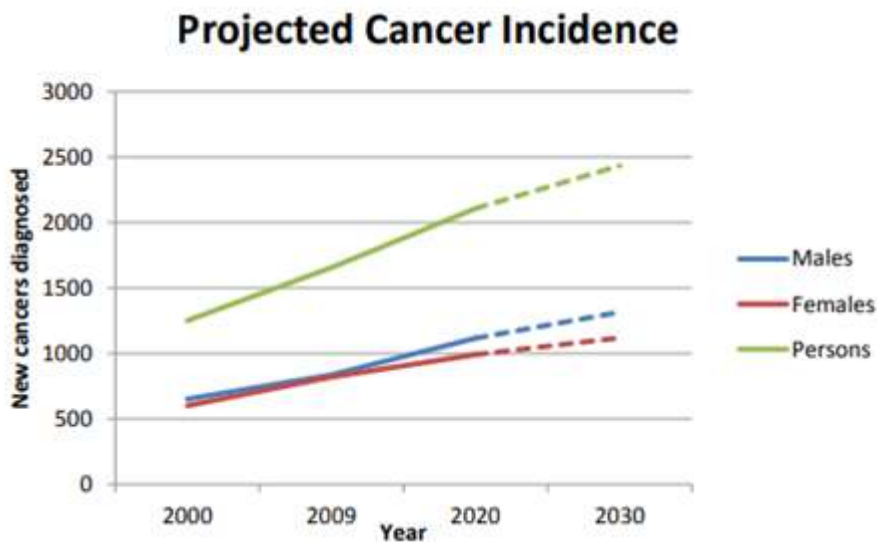


Scene setting

### 2.3. CANCER IN MALTA

The projected growth trends as indicated in the local cancer plan, suggested that cancer incidence was expected to surpass 2100 new diagnoses per year by 2020, and approach 2500 annually by 2030 (Ministry for Health [Malta] 2017) (Figure 1).

Figure 1: Projected annual increase in the number of new cancer per year up to 2030 (Malta National Cancer Registry 2016)



However, a recent report by the International Agency for Research on Cancer (IARC) from the World Health Organisation (WHO), indicated that a total of 2500 individuals were diagnosed with cancer in 2020 in Malta (Sung et al. 2021). Consequently, there are increasing numbers of people diagnosed with or beyond a cancer diagnosis.

In 2020, there were an estimated 7636 people who were diagnosed with cancer in the last five years, living in Malta (Sung et al. 2021). Of those people living with cancer, prevalence is highest for patients who were diagnosed with cancer of the prostate in men and cancer of the breast in women (Sung et al. 2021).

## **2.4. PROSTATE CANCER**

An estimated 1.4 million men were diagnosed with prostate cancer worldwide in 2020 (Ferlay et al. 2021). Prostate cancer incidence rates vary more than 25-fold worldwide, with a high incidence in Western countries and low incidence in Eastern European and South-Central Asia. The high incidence rates in Western countries have often been attributed to the widespread practice of Prostate Specific Antigen (PSA) testing and subsequent biopsy in these regions (Marhold et al. 2022), leading to higher detection rates.

The use of PSA measurements as a screening tool for prostate cancer remains controversial. For example, the European Randomized study of Screening for Prostate Cancer (ERSPC) was initiated to evaluate the effect of screening with PSA testing on death rates from prostate cancer. This data has been updated with 16-year follow-up (Hugosson et al. 2019). Findings of this study suggest that with extended follow-up, the mortality rate remained the same and that population-based screening programmes result in increased diagnosis which has historically led to overtreatment with associated side effects. Currently there is insufficient evidence to support systematic screening, but there is increased interest in early individual detection (Mottet et al. 2021).

## **2.5. PROSTATE CANCER CLASSIFICATION**

Prostate cancer classification is used to combine patients with similar clinical outcomes and allows the development of treatment recommendations for these patient populations. To classify prostate cancer the 2017, Tumour, Node, Metastasis (TNM) classification for staging of prostate cancer (Brierley et al. 2017) and the European Association of Urology (EAU) risk group classification (Cooperberg et al. 2005) are used. The EAU risk group classification takes into account the PSA blood level, Gleason score grading system and TNM

## Scene setting

staging system and defines prostate cancer into low, intermediate and high-risk groups and is further divided into localised or locally advanced, see Table 1.

*Table 1: EAU risk groups for biochemical recurrence of localised and locally advanced prostate cancer (Mottet et al. 2021)*

Definition			
Low-risk	Intermediate-risk	High risk	
PSA < 10 ng/mL and GS < 7 (ISUP grade 1) and cT1-2a	PSA 10-20 ng/mL or GS 7 (ISUP grade 2/3) or cT2b	PSA > 20 ng/mL or GS > 7 (ISUP grade 4/5) or cT2c	any PSA any GS (any ISUP grade) cT3-4 or cN+
Localised			Locally advanced
GS = Gleason score; ISUP = International Society for Urological Pathology; PSA = prostate-specific antigen; cN+ = clinically positive lymph nodes;			

The grading system for prostate cancer is based on the histological tumour patterns. In the original Gleason grading system, five Gleason grades (1-5) were distinguished and in 2014, the International Society of Urological Pathology (ISUP) endorsed a grading system that limited the number of prostate cancer grades, ranging them from 1 (low) to 5 (high) (Epstein et al. 2016).

Men diagnosed with prostate cancer have a favourable long term overall and cancer-specific rate of survival, irrespective of treatment option (Carioli et al. 2020). For men diagnosed with localised prostate

## Scene setting

cancer a range of treatment options are available, such as radical prostatectomy, external beam radiotherapy, brachytherapy or active surveillance (Mottet et al. 2021). Since there is no consensus regarding the optimal treatment option, prostate cancer treatment guidelines recommend that patients' preferences should be considered. The central consideration involves weighing the expected benefits against likely side effects so that the patient can make an informed treatment decision (Mottet et al. 2021).

Given that men affected by prostate cancer are living with the consequences of treatment for many years, the impact of such treatment and their QoL are important considerations. In the next section, an overview of the most common treatment options is provided including common side effects.

## **2.6. PROSTATE CANCER TREATMENT**

Treatment options for men diagnosed with prostate cancer vary according to the risk classification outlined previously and patient preferences. In this section the most commonly used treatment options, which are currently offered to men in the local setting, are presented. These include external beam radiotherapy treatment, brachytherapy treatment, prostatectomy and hormonal treatment. Some men may be offered a deferred treatment option, such as active surveillance or watchful waiting, where men do not undergo immediate treatment but are monitored. Such cases are not included in this section because such an approach does not involve any active treatment. The different treatment options will be presented in this section including common side effects associated with each treatment are also presented. In addition, treatments that are presented in this section may also be given in conjunction in order to help improve the health outcomes.

## Scene setting

### 2.6.1. Radical Prostatectomy

Radical prostatectomy (RP) involves the surgical removal of the entire prostate with its capsule intact and the seminal vesicles. Surgical approaches have evolved from perineal and retropubic open approaches to laparoscopic and robotic-assisted techniques (Hakenberg 2018). Although recommendation regarding one technique over another cannot be made with the current available data, the trade-offs between the risk of positive margin versus early continence recovery should be discussed with prospective patients (Mottet et al. 2021). Erectile functioning may be compromised following RP, whereas preservation of the neurovascular bundle may spare erectile functioning (Walz et al. 2016). Although many patients who have undergone RP experience a return to urinary continence (De Nunzio et al. 2019), temporary urinary incontinence is common early after surgery, reducing the QoL.

### 2.6.2. External Beam Radiotherapy

Advanced treatment techniques, such as Intensity-modulated radiotherapy (IMRT) or volumetric modulated arc therapy (VMAT) with image-guided radiotherapy (IGRT), are widely recognised as the best approach for external beam radiotherapy treatment (Mottet et al. 2021). These approaches employ dynamic multi leaf collimators, which automatically and continuously adapt to the contours of the target volume seen by each beam. Such techniques allow for a more complex distribution of the dose to be shaped around the target structure and can reduce acute genitourinary (GU) and gastrointestinal (GI) toxicities when compared with traditional three-dimensional conformal radiotherapy (3D-CRT) (Viani et al. 2016). However, GI and GU side effects are common during and after external beam radiotherapy treatment (Sutton et al. 2021). In addition, sexual side effects such as erectile dysfunction, orgasmic dysfunction, changes in

## Scene setting

penile morphology and sensory disturbance in the penis may occur following external beam radiotherapy treatment (Frey et al. 2017)

### 2.6.3. Brachytherapy

Brachytherapy involves the placement of radioactive seeds or sources into the prostate to deliver the radiation dose. Brachytherapy can be delivered using low dose rate (LDR) or high dose rate (HDR). For LDR brachytherapy, radioactive seeds are permanently implanted into the prostate. For HDR brachytherapy, radioactive sources are placed temporarily into the prostate (Zaorsky et al. 2017). Although side effects from LDR brachytherapy have been reported to be relatively equivalent to side effects from external beam radiotherapy treatment (Morris et al. 2017), the incidence of acute proctitis was reduced in the brachytherapy group. Acute side effects of HDR brachytherapy suggest lower rates of GI side effects, but a higher incidence of urinary retention (Zaorsky et al. 2017).

### 2.6.4. Hormonal treatment

Hormonal treatment or androgen deprivation can be achieved by suppressing the secretion of testicular androgen in different ways. The most commonly adopted method is the use of luteinising-hormone-releasing hormone agonist (LHRH) (Crawford et al. 2019). In the local setting, Goserelin acetate (ZOLADEX®) is most commonly used and is given at three monthly subcutaneous implants. Hormone treatments are effective in reducing testosterone levels which are the responsible for the growth prostate cancer cells. Although hormone treatment is usually well tolerated treatment by prostate cancer patients, many experience side effects that could significantly impair their health related QoL (Alibhai et al. 2015). Men undergoing hormone treatment may suffer from physical, sexual and psychological side effects. Physical side effects include weight gain, loss of muscle mass, fatigue, loss of body hair, genital shrinkage as well as feminising changes

## Scene setting

(e.g., hot flushes and gynaecomastia). Sexual side effects may include a decreased libido and erectile dysfunction. Additionally, men may suffer from psychological side effects such as emotional changes (e.g. change in mood), potential memory loss and depression (Wibowo et al. 2019; Abufaraj et al. 2021).

### 2.6.5. Combination of treatments

Whilst the different treatment options have been presented in isolation, it is important to note that men diagnosed with prostate cancer may undergo a combination of one or more treatment options. Whilst men diagnosed with low-risk disease may be offered individual treatment such as surgery or external beam radiotherapy treatment, men diagnosed with intermediate- or high-risk disease are commonly offered a combination of treatments (Mottet et al. 2021).

For example, localised high-risk prostate cancer patients may be offered external beam radiotherapy treatment in combination with a brachytherapy boost to the prostate (Morris et al. 2017) and long term (usually two to three years) hormone treatment (Mottet et al. 2021). In addition, it has been estimated that between 5-20% of men undergoing radical prostatectomy continue to have detectable PSA after surgery (Wiegel et al. 2015). These men may benefit from early aggressive multimodal treatment including external beam radiotherapy treatment and hormone treatment (Mottet et al. 2021). Combining treatment options may lead to a cumulation of side effects and therefore may have a negative outcome on the QoL (Kerleau et al. 2016).

## **2.7. IMPACT OF PROSTATE CANCER TREATMENT ON FEMALE SPOUSES**

Men undergoing prostate cancer treatment can experience a range of treatment-related side effects. The physical related consequences are primarily associated with sexual, urinary and bowel functioning. Along

## Scene setting

with the emotional and practical challenges that accompany the diagnosis and treatment of prostate cancer, the high rates of permanent erectile, urinary and bowel dysfunction can pose a significant challenge to men's psychological well-being (Yiannopoulou et al. 2020).

Although prostate cancer is unique to men, diagnosis and treatment can negatively impact their partner as well (Green et al. 2022). It has been suggested that psychological distress among female partners is higher than levels reported by patients (Green et al. 2022). Furthermore, challenges in communication, role changes, changes in attitude and interruption in intimacy have been reported (Bamidele et al. 2019; Collaço et al. 2021). A diagnosis of prostate cancer can be considered a major life stressor that can disrupt the lifestyle and routine of couples (De Sousa et al. 2012).

The way in which couples cope and adjust to the impact of prostate cancer treatment may also be influenced by the health policies and the cultural and social background in which they live. In the next section an overview of the European and local health policies and the cultural background is presented.

## **2.8. HEALTH POLICIES AND CULTURAL BACKGROUND**

This current study took place in Malta which is a small archipelago of five islands in the Mediterranean. Malta is influenced by European cultures as an economic and political society. The country became a full member of the European Union in May 2004 (European Commission 2022). In this section, the European and local health policies which are of interest to this study are provided together with an overview of the cultural setting that may influence the adjustment of couples following prostate cancer treatment.



## Scene setting

### 2.8.1. European health policies

Malta, as a full member of the European Union is influenced by European health policies. Throughout the duration of this study several health policies have been drafted and implemented in the EU that also have informed local health policies. One of such initiatives was the European Partnership for Action Against Cancer (EPAAC) which was launched in 2009, after the European Commission published its Communication on Action Against Cancer: European Partnership. One of the key aspects of this initiative was that all member states were required to draft a national cancer plan to reduce the number of cancer cases and mortality rates and improve the quality of life of cancer patients. This has led to the development of the first ever national cancer plan in Malta (Ministry for Health, the Elderly and Community Care [Malta] 2011).

More recently, the European Commission presented Europe's Beating Cancer Plan (European Union 2021). This plan is a key EU public health initiative and a cornerstone of European health union process launched in November 2020 (European Commission 2020). Although the responsibilities of health primarily lie with the individual member state, Europe's Beating Cancer Plan sets out action to support member states at different stages of the disease (European Union 2021). This plan consists of 10 flagship initiatives and of particular interest for my study is the initiative to improve the quality of life for patients, survivors and carers.

Europe's Beating Cancer Plan has highlighted that due to the improvements in detection and treatment, it is expected that a higher number of survivors and carers will be living with the consequences of cancer treatment (Ferlay et al. 2021). They may experience significant challenges that could often be avoided or mitigated by the cooperation of relevant health and social care systems. One of the initiatives launched as part of the Europe's Beating Cancer Plan by the

## Scene setting

European Commission is the 'Better life for Cancer Patients Initiative' which will focus on follow up care (European Union 2021). This initiative aims to provide a cancer survivor smart card to summarise the clinical history and facilitate and monitor follow-up care including patients' experiences. Such card will enable to connect the patient with healthcare professionals to improve communication and coordination around medical follow-up (European Union 2021).

### 2.8.2. The Maltese National Cancer Plan

To tackle the cancer problem at a national level, the first ever Maltese national cancer plan was drafted in 2011 (Ministry for Health, the Elderly and Community Care [Malta], 2011). This cancer plan was the result of discussions with various stakeholders over a three-year period and was designed to reduce incidence, prolong survival and ensure the best QoL possible for cancer patients. The plan covered a five-year period from 2011 to 2015 and set out the objectives and measures which needed to be addressed to bring the desired improvements to tackle the national cancer burden.

The national cancer plan aimed to introduce a number of improvements, these included the strengthening of the breast cancer screening programme and the introduction of colorectal and cervical screening programmes. Besides the introduction of these various screening programmes, another major improvement in the delivery of treatment was the realisation of a new cancer hospital where all services for oncology patients were combined in one centre. The new cancer hospital, which provides all the modern service modalities needed by cancer patients, is a cornerstone of this first national cancer plan. The new oncology centre was officially inaugurated in September 2015 (Laspina, 2015).

The inauguration of the new hospital with modern equipment has changed the treatment for many cancer patients. Following the

## Scene setting

transfer to this new hospital, several techniques have been implemented, such as high precision delivery of radiotherapy treatment using advanced techniques such as IMRT and VMAT. This technological advancement in radiotherapy treatment provides the potential to improve tumour irradiation and spare organs in close proximity to the tumour (Rehman et al. 2018).

Following the initial cancer plan, a new cancer plan was published covering a five-year period from 2017 to 2022 (Ministry for health [Malta], 2017), during which period this study took place. The ultimate aim of the cancer plan is to improve a number of identified outcomes and to improve patients' experiences and QoL which is of particular interest for this study.

The national cancer plan recognises that many of the treatments used in cancer care have a potential for long-term health consequences. The lack of attention to these issues often leads to poorer QoL for patients and augmented pressures on their caregivers. A fundamental guiding principle, as indicated in the national cancer plan, is the participation of patients in the care process:

“The model of care that is applied should be based on communication with patients and shared decision-making whenever possible and appropriate. Cancer services need to be patient-centred and should take account of patients', families' and carers' views and preferences (particularly those affecting their quality of life)” (Ministry for health [Malta], 2017 p 56)

### 2.8.3. Cultural background

Culture has been described as 'a potent force in shaping beliefs, moderating behaviours and giving meaning to experiences' (Walker et al. 1995, p49). Dein (2004) argued that the way in which different

## Scene setting

groups of people respond to a life-threatening disease is highly dependent on their cultural background. This section provides some background information regarding the social and cultural background in Malta, particularly in relation to gender roles within society, family, and religion.

### 2.8.3.1. Gender roles and society

There is some evidence to suggest that, within the Maltese culture, men and women tend to align themselves to more traditional gender values (Mifsud, 2016). In addition, the employment rate for females in Malta remains low (52.2%) when compared to males (78.3%) (Vassallo, 2016). Although there is a difference in employment rates in all age groups, the greatest difference between male and female employment is in the higher age group (age 55 to 64 years). Out of the inactive women in the paid workforce, 31% stated personal or family responsibilities. These figures emphasise the more traditional roles adopted within families in Malta, where females are more likely to permanently leave their job to take care of family responsibilities (National Statistics Office [Malta], 2019).

### 2.8.3.2. Family relationships

Within the context of Maltese society, there is a relatively high degree of family proximity, which has been indicated to be of value during cancer diagnosis and treatment as family may provide support and reciprocity (Briguglio and Tedesco 2016). According to Abela (2005), Malta has characteristics of a face-to-face society whereby the family is an important aspect in one's public and private identity. In line with the face-to-face community, Baldacchino (2006) indicates that, during illness, family relationships typically become closer and the family and neighbours try to support the patients in various ways, such as, by visiting them in hospital and assisting them on their return to the community. These family relations may also have an impact on how couples adjust following a prostate cancer diagnosis and treatment.

## Scene setting

### 2.8.3.3. Religion

Religion may also influence how couples deal with a prostate cancer diagnosis and treatment in the local setting. Malta has a strong Christian orientation with most of the population still identifying as Roman Catholic. According to a Eurobarometer survey conducted in 2019, 83% of the population identified themselves as Catholic (European Commission, 2019). The Catholic Church also continues to play an important role in marriage preparations, rituals, and dissolutions. Religion or maintaining one's religious faith and practices may also be beneficial for couples when dealing with the negative impact of a prostate cancer diagnosis and treatment (Palmer Kelly et al. 2020). Religious values and practices may provide hope, comfort and meaning during a diagnosis and treatment for cancer (Puchalski 2012) and therefore religion may have an important impact on the adjustment of couples in the local setting.

## **2.9. CONCLUSION**

Prostate cancer is the most commonly diagnosed cancer in men in Europe and in Malta (Ferlay et al. 2021). Due to early detection and improvement in treatment, a large number of men are living with the consequences of prostate cancer treatment. Besides the impact on men, treatment and the related side effects may also have a negative impact on spouses. This current chapter has presented an overview of the current burden of prostate cancer in Europe and in Malta. Despite emerging evidence based on the experiences and impact of prostate cancer on couples, further investigation could reveal potential areas that may be targeted for intervention in Malta and, possibly in other countries. To identify current knowledge and relevant gaps in existing research, a literature review was conducted, and this is discussed in more detail in the following chapter.

## **CHAPTER 3. LITERATURE REVIEW**

### **3.1. INTRODUCTION**

This chapter provides an in-depth review of the literature that considers the impact of prostate cancer from the perspectives of men and their spouses. The search strategy is presented, demonstrating how a systematic approach to searching, retrieving, and reviewing the relevant literature was undertaken. The literature search related to this topic revealed a large number of quantitative and qualitative studies, and literature reviews, which examined the impact of prostate cancer on male patients and their partners/spouses. As a large number of potentially relevant studies were identified, the literature was further synthesised based on the methodologies adopted (e.g., quantitative or qualitative) and the characteristics that may influence the impact and adjustment to prostate cancer (e.g., age of men at diagnosis and treatment option). In addition, studies were appraised using the Critical Appraisal Skills Programme (CASP) appraisal tools (Critical Appraisal Skills Programme 2019) to identify the main body of evidence for the relevant category, and the remaining articles used to provide further context to the review.

The literature review will discuss four categories: QoL changes experienced by couples over time, impact of age on the adjustment of couples, impact of treatment option on the adjustment of couples and the impact of a prostate cancer treatment on the life and relationship of couples.

### **3.2. LITERATURE SEARCH STRATEGY**

A systematic approach to searching the literature was undertaken with the assistance of a university librarian, covering five databases that

## Literature Review

could potentially include relevant literature (ScienceDirect, PubMed, Age line, Psych info and CINAHL) and the reference list of relevant retrieved papers was also hand-searched. The following search terms were used (in various combinations) to guide the literature search: “Prostate cancer” OR “Prostatic neoplasm” AND “Couple OR Spouse OR Dyad” AND “Quality of Life” OR “Relationship” OR “Intimacy” OR “Interpersonal” OR “Coping “OR “Adjustment “. To ensure that relevant evidence captured salient papers and, where possible, was also based on up-to-date information which accounted for recent developments in treatment and care, the literature search was limited to the last 15 years (2006 – 2021).

Eligible studies were restricted to research focusing on patients diagnosed with localised prostate cancer who received treatment with a curative or radical intend. The purpose of this review was to gain a synthesised view of the impact of prostate cancer on the life and relationship of couples in order to identify potential gaps in existing knowledge. Thus, this review included only those studies which reported an impact on men and their partners. As the impact of prostate cancer can include physical, social and psychological consequences, studies that assessed these aspects were included. Studies that evaluated the impact and outcomes of prostate cancer treatment included those studies that assessed QoL, communication, distress, sexual functioning, intimacy, and studies that focused on couples’ adjustment such as coping, social impact and changes in the relationship.

Studies needed to include an assessment component after primary treatment of prostate cancer to assess the impact of diagnosis and treatment on couples. Inclusion and exclusion criteria were therefore employed to maintain consistency in selection of research articles for review.

Inclusion criteria:

## Literature Review

- Articles published in English;
- Men diagnosed with localised prostate cancer;
- Both men and partners included and assessed in the study;
- A focus on at least one of the following aspects: impact of treatment on couples, their relationship and/or intimacy or interpersonal adjustment (e.g., coping, psychosocial adjustment, QoL);
- Articles published between 2006 – 2021 due to advancement in prostate cancer treatment and the delivery of care;
- Includes an assessment component following primary treatment to evaluate the impact of the treatment.

### Exclusion criteria:

- Included other cancer diagnosis (e.g., breast or colon);
- Studies that included an intervention (e.g., psycho-social) and assessed the outcomes of such interventions;
- Book chapters;

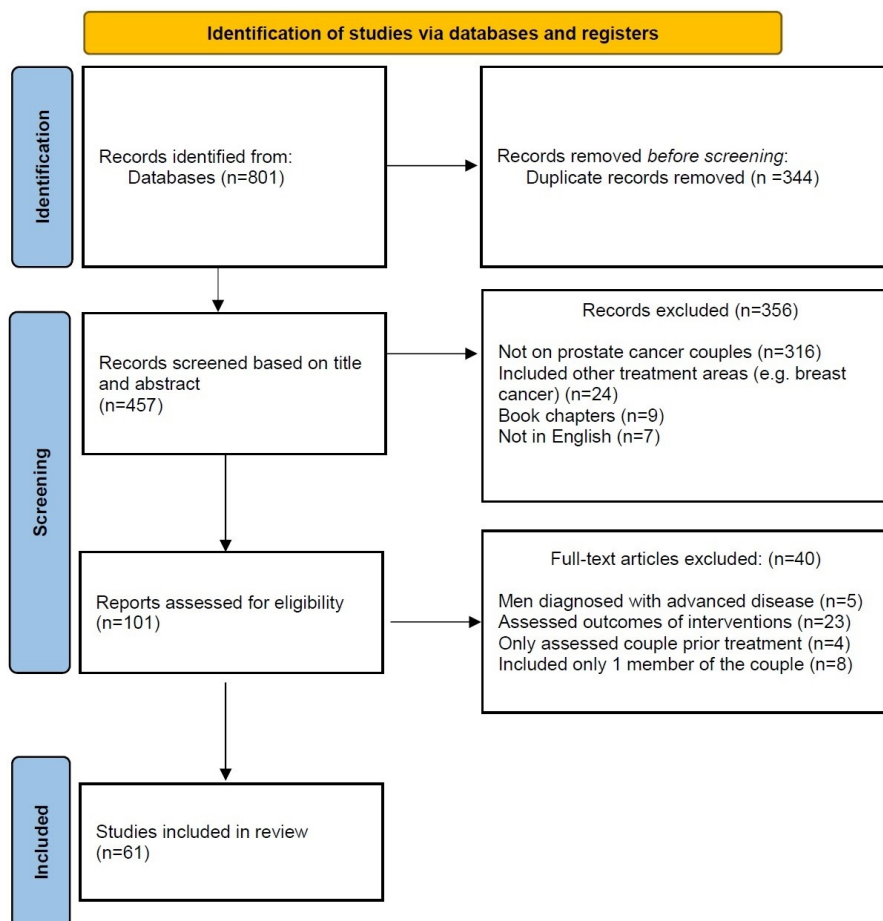
The initial search revealed a total of 801 records. Following the removal of duplicates, 457 articles were screened and reviewed. The screening process was based on a review of the title and abstract of each paper to establish potential relevance and eligibility. Consequently, a further 356 articles were excluded as they did not meet the inclusion criteria. The most common reason for the exclusion was that most studies were not focused on prostate cancer in couples; they only focused on men (most commonly) or their partners. The full text of the remaining 101 articles was downloaded and reviewed in full. Following a review of these articles 40 articles were excluded as they assessed the outcome of an intervention (n=23), included only 1 member of the couple (n=8), focused on advanced disease (n=5) or



## Literature Review

only assessed couples prior to prostate cancer treatment (n=4) (Figure 2).

Figure 2: Identification and screening of literature articles



### 3.3. SYNTHESIS OF THE LITERATURE

The initial literature search revealed 61 articles and included quantitative studies (n=34), qualitative studies (n=16), mixed methods studies (n=1), and literature reviews with practice recommendations (n=10) which focused on couples dealing with prostate cancer. Following this initial review, I decided to exclude the literature reviews and practice recommendations (n=10) as these did not include original data and therefore did not provide new insights. The remaining 51

## Literature Review

articles were conducted in a range of different countries. Most studies were performed in the United States of America (USA) (n=26), followed by the United Kingdom (UK) (n=8), Canada (n=7), Australia (n=4), Germany (n=2), Taiwan (n=1), Finland (n=1), and the Netherlands (n=1). One study was performed in several countries, these included Ireland, Australia, UK and USA. This therefore suggests that the main body of published evidence is related to couples undergoing treatment in these countries and healthcare settings. Due to the large number of potentially relevant studies identified during the literature search, the literature was divided into broader groups and categories. These different groups and categories were based on study methodologies adopted and characteristics that may influence the experience and adjustment of couples. These characteristics included QoL changes over time, age of men at diagnosis, impact of treatment option and impact on the couple's life and relationship. For each of these categories, a brief summary is provided, and a detailed process of the selection and synthesis of the literature can be found in Appendix One. The selection process used to determine the main body of evidence for each category included critical appraisal using the relevant, design-specific CASP appraisal tools (Critical Appraisal Skills Programme 2019). The CASP appraisal tool is a checklist/criteria-based tool for quality appraisal in healthcare-related evidence synthesis (Hannes and Macaitis 2012).

The CASP appraisal tool was used to identify strengths and weaknesses of each paper and to determine the overall quality of the studies. Assessing the quality with the CASP appraisal tool allowed for the organisation of articles on quality, such that studies deemed to be of higher quality can contribute more to the synthesis compared to the lower quality studies (Long et al. 2020). The initial process of the literature synthesis was to organise the studies based on overall quality of the studies for each category to purposely select high quality

## Literature Review

studies that were deemed appropriate for the aim and objectives of this review.

In addition, whilst the CASP tool can provide meaningful information about the general quality of the studies, some authors have agreed that essential criteria may provide further information about the specific quality appraisal criteria (Carroll et al. 2012; Franzel et al. 2013). For this review, additional criteria were set for each category to determine what was considered to be important for the aim and objectives of this review (see appendix one). For example, during the appraisal process, it was noted that the recruitment process adopted in some studies may have influenced their findings. For example, some studies recruited couples from support groups, which may have resulted in more well adapted couples participating in their studies. In addition, other studies included couples from different phases of the illness trajectory (newly diagnosed, biochemical recurrence or advanced disease). Therefore, this could have resulted in some couples who, having lived with prostate cancer for a long period of time, may have influenced the findings. Following the overall quality appraisal, specific criteria were set for each category to purposely select studies that were used as the main body of evidence.

The main body of evidence, following the selection and appraisal process, resulted in the purposive selection of 13 articles (based on overall quality and relevance to the research aim/question) which are presented as the main body of evidence, with the remaining articles (n= 38) used selectively, where appropriate, to provide further context.

### 3.3.1. Quality-of-life changes over time

To determine the impact of time on the adjustment of couples to changes associated with prostate cancer treatment and to identify a time period that may require further investigation, all quantitative articles which had a longitudinal component were included in this category. Articles were critically appraised to determine the main body

## Literature Review

of related evidence. During the appraisal it was identified that some articles included men from three different phases of the illness trajectory (newly diagnosed, biochemical recurrence or advanced disease). Therefore, this could have resulted in some men who, having lived with prostate cancer for a long period of time, may have influenced the findings. In addition, other studies did not specifically focus on the QoL scores following prostate cancer treatment, but instead investigated other aspects, such as changes in the dyadic communication process over time or congruence between men and spouses regarding the severity of side effects (see Appendix One).

### 3.3.2. Age-specific considerations

Prostate cancer is rarely diagnosed in men younger than 50 years, and around 95% of all prostate cancer occurs in those over the age of 50 years (Guo et al. 2019). The impact of a prostate cancer diagnosis on a man at the age of 60 years may vary, particularly when compared to the impact on a man who is diagnosed at the age of 80 years. Changes in work-related activities, social contacts, family situation and physical health may have an impact on the QoL of men following prostate cancer (Kurian et al. 2018) and therefore may also influence the adjustment of couples. However, my literature review only identified 6 articles that focused on a particular age group or specifically investigated differences between age groups (Appendix One).

### 3.3.3. Treatment-specific considerations

Although the different treatment options for prostate cancer can be considered as relatively equally effective in terms of survival (Carioli et al. 2020), each treatment option may have its own unique side effect profile (Mottet et al. 2021) and consequently, may have an impact on the experiences and adjustment to prostate cancer. Most studies identified in the literature review included men who underwent a range

## Literature Review

of treatment options such as surgery, external beam radiotherapy and brachytherapy. Therefore, this might limit the treatment-specific needs that may be present in this population. A total of seven studies focused on a specific treatment option, including surgery (n=4) and Androgen Deprivation Therapy (ADT) (n=1), and a further two studies were identified that compared ADT with non-ADT (Appendix One).

### 3.3.4. Impact of prostate cancer treatment on couples' lives and relationships

To determine the impact of a prostate cancer on the lives and relationships of couples, the remaining qualitative studies (n=11), the remaining quantitative studies (n=11) and mixed method study (n=1) were included in this group. In order to provide an in-depth understanding of the impact and challenges that these couples may face following prostate cancer treatment, the main body of evidence was related to qualitative studies with quantitative studies providing some further insight into the phenomena. The qualitative studies were critically appraised using the relevant CASP tool in order to identify the main body of evidence (Appendix One).

## **3.4. QUALITY-OF-LIFE CHANGES OF COUPLES OVER TIME**

Assessment of outcomes following prostate cancer treatment entails measuring not only the duration of survival, but also the impact on QoL (Chien et al. 2019). QoL is a multidimensional construct that includes physical, emotional, functional, and social wellbeing (Jitender et al. 2018). Prostate cancer and its treatment often result in symptoms and difficulties that can affect a range of QoL issues. Prostate cancer treatment can have a profound impact on the QoL of men and it has been reported that QoL scores may change significantly over time following prostate cancer treatment (Lardas et al. 2017). Whilst the negative impact on the QoL of men is commonly reported, less

## Literature Review

information is available with respect to how the QoL score of men influences the QoL score of their partners (and/or vice versa). The literature review identified several studies which investigated the impact of prostate cancer over time, and these are further presented in the next section.

### 3.4.1. Quality-of-life changes over time

Eisemann et al., (2014) undertook a quantitative longitudinal study to investigate the QoL scores of both men and their partners and included 293 couples from Germany. In this study, the men were diagnosed with early prostate cancer (T1-T3b) and their treatment regime included radical prostatectomy or external beam radiotherapy treatment. Baseline QoL scores were collected prior to the commencement of treatment, with repeated measurements at 3, 6, 12 and 24-months post treatment. In total, 28.8% of QoL data was missing (over all five observation time points) and only 130 partners completed the questionnaire at all five time-points. The QoL was measured by the global health and QoL status of the European Organization for Research and Treatment of Cancer (EORTC) Core QoL Questionnaire (QLQ-C30) (Aaronson et al. 1993). Eisemann et al. (2014) indicated that the QLQ-C30 was the most used and validated tool available in the German language, but no further tests were done on the population under investigation. In addition, in order to measure specific prostate cancer symptoms, the EORTC items constipation and diarrhoea, the EORTC fatigue scale, the urinary urge syndrome scale of the prostate-specific module (PSM) (Bestmann et al. 2007), and the erectile function scale of the International Index of Erectile Function (IIEF) (Rosen et al. 1997) were included in the model as cancer-related factors.

Eisemann et al. (2014) suggested that almost half the couples indicated sexual problems at baseline, with a higher percentage among partners (49.8% versus 44.2% respectively). Approximately

## Literature Review

half of these patients and partners dealt with related problems caused by treatment using an avoidant coping strategy and the other half with an active coping strategy, with more partners reporting an active coping strategy. In the follow-up period the percentage of couples with sexual problems rose to approximately 80%, with similar scores reported by both men and their partners. This study suggests that spouses had a lower QoL score at all observation time points. The QoL scores of spouses were subject to some variations with the lowest scores reported at baseline, some improvement was noted at three months follow-up and a further decline in the following nine months. However, these changes in mean QoL scores were not clinically relevant, as determined by a change of more than 10 points in the QoL scale score (Osoba et al. 1998). The QoL score of the men in this study remained relatively stable throughout all the assessment points, there was some improvement over time, but this trend was not significant. Although Eisemann et al. (2014) did not identify clinically relevant changes in the average QoL scores, it was suggested that the pace of adaption to related changes in QoL may vary between individuals. Eisemann et al. (2014) noted that clinically significant changes in QoL scores were identified in 90.3% (n=234) of partners at least once during the study period, at 10-point higher or lower QoL scores when compared with baseline. However, such trends were not observed in the mean scores since individual increases and decreases in scores may cancel each other out. These individual temporal changes could be explained by personal, disease-related or appraisal/coping factors. Some limitations, identified in the study by Eisemann et al. (2014), included the fact that a large number of partners did not complete all the five assessment points, with only 44% (n=130) of the partners having completed all assessment periods. The questionnaires were self-completed by patients and their partners, this could have resulted in collusion between couples or in the reporting of socially desirable answers.

## Literature Review

Galbraith et al. (2008) performed a longitudinal survey to investigate the changes in health-related QoL over time for couples dealing with prostate cancer. This study explored health-related outcomes before the men started treatment and at six, 12 and 18 months after treatment. This study included a convenience sample of 216 couples affected by prostate cancer, with the men diagnosed with localised prostate cancer (Stage I and II). Patients were initially recruited in person or by telephone by the investigator who was based in a university medical centre in the South-Western USA. Treatment strategies included external beam radiotherapy, surgery and watchful waiting. Couples were required to complete questionnaires before initial treatment and at six, 12- and 18-months following treatment. QoL was assessed with the Quality-of-Life index (QLI) (Padilla et al. 1983). As a general measure of health status, the Medical Outcome Study General Health Survey (SF-36) was used (Ware and Sherbourne 1992), and to assess the quality of marriage and dyadic adjustment, the Dyadic Adjustment Scale was utilised.

Galbraith et al. (2008) suggests that prostate cancer can cause a lasting complex combination of physical, psychological and social effects which continue to be experienced long after treatment is completed. Before starting treatment, patients reported statistically significantly better scores in relationship satisfaction ( $p=0.05$ ), physical role function ( $p=0.05$ ), emotional function ( $p=0.01$ ), mental health ( $p<0.001$ ) and pain ( $p<0.001$ ). Partners reported better health-related QoL than patients at six months ( $p=0.001$ ), 12 months ( $p<0.001$ ) and 18 months ( $p=0.009$ ) after treatment. In relation to mental health, patients reported better scores at six months ( $p=0.04$ ) and 12 months ( $p=0.04$ ), but at 18 months their partners reported a better mental health score ( $p=0.02$ ).

Patient scores before treatment significantly predicted partner scores on five of the 10 outcome measures, these included relationship



## Literature Review

satisfaction, emotional role functioning, energy, mental health and social functioning. At 18 months, patient scores predicted partner scores on seven of 10 outcome measures, including health-related QoL, relationship satisfaction, physical functioning, physical role functioning, emotional functioning, energy and social functioning. Patient scores predicted partner scores on several items at all four data collection time points, indicating the importance of dyadic adjustment. Patient and partner scores were most strongly related to relationship satisfaction and least related to their specific health. Partner responses indicated that patients influenced the health-related QoL they were experiencing after treatment.

The Galbraith et al. (2008) study suggests that both the physical and mental health component summary score were lowest at 12-months post-treatment (Galbraith et al. 2008). This could indicate that this recovery point may be particularly important in the illness trajectory. Furthermore, this study suggests that patients reported better health-related QoL scores when compared to their spouse before treatment started, which switched over at six months when their partner reported relatively better QoL scores. This could be due to the adverse treatment reactions experienced by the patients which subsequently appear to negatively impact their health related QoL scores. The six to 12-month timeframe following treatment seems to be an important period when a changeover takes place in the physical and mental health scores of men and their partners. Although the lowest average scores were reported at 12-months post-treatment, it is not clear whether these couples experienced some unmet supportive care needs during this period.

Some limitations of the Galbraith et al. (2008) study included that only average ages for each treatment option were reported, which makes it challenging to identify any age-specific changes in QoL scores. Furthermore, it involved the use of a self-reported questionnaire which

## Literature Review

could have led to couples completing the questionnaire together or providing socially desired answers.

In contrast to Galbraith et al. (2008), Song et al. (2011) indicated that patients always reported better QoL scores than their partners (four, eight and 12 months) following the completion of treatment. Song et al. (2011) investigated the relationship between QoL in patients and partners and how baseline demographics, cancer-related factors, and time-varying psychosocial and symptom covariates affected their QoL over time in the USA. This longitudinal study assessed men and their partners at baseline and subsequently at four, eight- and 12-months follow-up. This study included a total of 134 couples and QoL was measured with Functional Assessment of Chronic Illness Therapy general scale (FACT-G) (Cella et al. 1993). The FACT-G scored high reliability for both patients and partners at baseline (Cronbach alpha 0.9). The lower scores of partners in the study could suggest that there may be a greater negative impact of prostate cancer on partners. Song et al. (2011) did not record any improvements in QoL scores for patients or partners at four, eight and 12 months following the completion of treatment. Although no differences in QoL scores were noted, this study grouped patients into three phases of disease (localised, recurrence or advanced) which could have influenced the results, since two of the patient groups (rise in PSA and metastatic disease) could have been diagnosed and living with prostate cancer and its related treatment effects for many years.

Harju et al. (2018) performed a longitudinal survey to identify changes in the marital relationship and in health related QoL at diagnosis and six months post diagnosis. Similarly, to Eisemann et al. (2014), Harju et al. (2018) noted no changes in QoL scores of either men or their spouses at six months. However, this study highlighted a decline in the marital relationship at six months. This indicates that other aspects could have contributed to this decline, such as concerns about the

## Literature Review

men's illness, problems with sexual functioning or communication issues. Wu et al. (2013) suggested that the illness beliefs of spouses (for example spouses believing that the treatment would 'control their loved one's illness') led to improvement in QoL scores for the patient. Therefore, this study highlighted the important influence and interaction that spouse illness beliefs may have on patient QoL scores. Although spouses may have an important influence on the QoL score of patients, other factors may have a negative impact on the QoL score of both men and their spouses. For example, Wood et al. (2019) suggested that perceived cancer stigma by men may have a negative impact on the QoL scores of both patients and their partners, but not their relationship satisfaction. Stigma is a socially constructed phenomenon wherein individuals with diseases that differ from healthy individuals are discredited (Jones and Corrigan 2014). The findings of Wood et al. (2019) may therefore highlight the important influence that the social and cultural background may have on QoL scores of both patients and their spouses.

Ross et al. (2016) indicated that at the time of diagnosis, the average mental and physical health scores for spouses was significantly lower when compared to patients' scores ( $p < 0.001$ ). These results align with Galbraith et al. (2008) and Eisenman et al. (2014), who also indicated that partner scores were significantly lower than patient scores in physical and mental health prior to the commencement of treatment. Although partner scores were lower before treatment and patient scores appeared to be lower following treatment, it is not clear how these men and their partner coped and adjusted during this phase. Varner et al. (2019) and Ross et al. (2016) noted improvements in the physical and mental health of patients at 12 months. Spouses did not follow the same trend, and Ross et al. (2016) noted a further decline in physical health at six months, with little improvement at 12 months. A decline in the physical health of spouses was also observed by Galbraith et al. (2008), with some improvements at 18 months post-

treatment. Therefore, it appears that the first year following prostate cancer treatment is a particularly important phase in the recovery from prostate cancer. However, studies which focus on this particular period are limited.

### **3.5. AGE-SPECIFIC CONSIDERATIONS**

The occurrence of cancer in men aged 50 to 64 can result in early retirement, and this may cause anger and frustration related to being deprived of a physically and financially healthy retirement (Peterson 2013). For this age category work continues to be a major source of social status, self-esteem, social contacts, and financial well-being (Yu Ko et al. 2020). Men and woman in their mid-60s and early 70s typically enter retirement and a transitional status. Although many people welcome retirement, it can cause stress which can in turn challenge their self-esteem (Mukku et al. 2018). The absence of work-related responsibilities can lead to a feeling of uselessness and depression. Changes in the social domain due to an absence of work-related activities can lead to loneliness (Mukku et al. 2018). Although many adults are still in good health, they may begin to experience physical changes related to ageing and co-morbid conditions. As couples move beyond the mid-70s, they begin to experience a greater decline in physical abilities. Couples in long-lasting relationships may rely on each other to meet daily challenges and maintain independence.

The occurrence of prostate cancer in different age groups may have various implications for the couple as outlined above, however only six studies identified in this review have been specifically designed to investigate age-specific considerations and these will be further presented in this section.

### 3.5.1. Development life stage and prostate cancer

Harden et al. (2006) undertook a qualitative study to explore the experiences of men with prostate cancer and their partners, according to their development life stage. This study included 15 couples from the three age categories (50-64 years, 65-74 years and 75-85 years) and aimed to expand the understanding of living with prostate cancer. Men were included in this study when their spouse was also willing to participate and when they fell into one of three illness phases: newly diagnosed (two - four months), biochemical recurrence (one - three months) or advanced stage (one - three months). Given that the study focused on the shared experience of couples, patients and partners were interviewed together in their home or in another suitable location, and the interviews lasted between 45-120 minutes.

Study findings identified three general themes which focused on the effect of prostate cancer on daily life, dyadic/family relationship and development issues which were specific age-related concerns. All couples indicated that the diagnosis and treatment had an impact on their daily lives. Men aged 50-64 years expressed concerns about fulfilling their perceived role within the family unit. Four of the men in this study talked about feeling depressed or mentioned receiving treatment for depression. For most couples who were still working, the prostate cancer diagnosis affected the patient's and/or the partner's ability to work. This can lead to financial strains and a reduction in social contacts due to an absence from work, putting additional pressure on the relationship. Although it was indicated that men expressed concerns about their ability to fulfil their role, this was not further explored. Fatigue was identified as one of the most troubling factors affecting participants' daily lives and interfering with their ability to work, complete daily tasks and participate in social activities. Financial worries were also reported in this age group and some of the men were subsequently dependent on their wife's income due to their

## Literature Review

inability to work. Therefore, this could have significantly impacted the roles and responsibilities within the couple's daily lives.

Although the results indicated differences between the various life stages, participants were further divided into three different phases (newly diagnosed, recurrence and advanced disease) which resulted in very small subgroups, in some cases containing only one couple. This made it difficult to identify notable similarities or differences between the different sub-groups. Furthermore, at the point of data collection this could have resulted in some couples living with the consequences of a prostate cancer treatment for a long period of time.

More recently, Collaço et al. (2021) undertook a qualitative study as part of a larger UK wide study: Life After Prostate Cancer Diagnosis (LAPCD) (Downing et al. 2016). Collaço et al. (2021) undertook in-depth individual interviews to explore the experiences of younger men (age <65 years) and their partners, affected by prostate cancer. Eligible participants who had completed the LAPCD questionnaire and indicated that they were willing to take part in a telephone interview were recruited to the study (Collaço et al. 2021). A maximum variation sample framework was developed to include a wide range of experiences; the men who participated underwent a range of different treatment options for prostate cancer. However, given that only a mean time since diagnosis (of 3.2 years) was reported, no information or details were provided with respect to when the men underwent their treatment. Findings noted that an overarching theme referred to the sense of 'us' or 'we-ness' in the relationship and was captured in the theme 'evolving couple identity'. As prostate cancer treatment and side effects caused changes to couples' relationships, couples had to find ways to integrate and manage old and new relational dynamics. A common behaviour identified within couples, particularly when the men were receiving hormone treatment, was 'distancing' from one another. The men reported that the hormone treatment impacted the

## Literature Review

dynamics in the relationship. A limitation of this study included the fact that couples underwent a range of treatment options for prostate cancer, limiting insight into treatment-specific needs or impacts. It was also not clear when the men had completed prostate cancer treatment. Time following treatment has an important impact on the QoL of men and their partners (Eisemann et al. 2014) and is therefore an important factor to consider in the adjustment of couples to the changes brought about by a prostate cancer treatment.

Although age-specific issues may influence how couples cope with prostate cancer, only six studies were identified which focused on specific age groups. Two other studies (Song et al. 2011; Winters-Stone et al. 2014), identified in the literature search, also noted differences between age groups. For example, Winters-Stone et al. (2014) reported that when patients with prostate cancer were younger (for example 60-70 years), the severity rating of symptoms was higher when compared with older patients (for example >70 years). Similar results have been identified by Song et al. (2011), who indicated that couples' QoL was also associated with the age of the partner, whereby younger partners (for example <60 years) reported lower QoL scores (Song et al. 2011).

Schindler et al. (2010) noted that older couples collaborated more frequently during everyday problem solving when compared with late-midlife couples. When older couples collaborated less frequently this had a negative impact on their well-being (Schindler et al. 2010). Similarly, Keller et al. (2017) noted that older couples tend to be retired and therefore spent much of their waking time together, which could benefit their well-being (Keller et al. 2017).

Chambers et al. (2013) further indicated that being younger and having a shorter time since diagnosis was associated with greater anxiety for patients. Although age may have an important role in the adjustment of couples, most studies use large age categories making

it difficult to identify specific needs for this group. In addition, the age range of groups tends to vary between the studies, with some identifying younger as below 60 years of age (Song et al. 2011), and others identifying men aged 60-70 as younger (Winters-Stone et al. 2014). Another study groups the men into three categories (for example 50-64, 65-74 and 75-85 age groups) according to their development life stages (Harden et al. 2006). These differences could therefore make it difficult to identify age-specific considerations that may be important in their adjustment following prostate cancer treatment.

### **3.6. TREATMENT-SPECIFIC CONSIDERATIONS**

Several prostate cancer treatment options are available as outlined in Chapter two, with each of these treatment options having its unique side effect profile. In addition to these different side effect profiles, some prostate cancer procedures can be completed in one day (for example surgery) or they may require daily visits to the hospital over a longer period of time (for example several weeks) in the case of external beam radiotherapy treatment (Mottet et al. 2021). These differences may therefore have a profound impact on the experiences of men and their partners, and could result in treatment-specific requirements. In this section, the literature relating to the difference in treatment options for couples will be presented and discussed.

#### **3.6.1. Impact of treatment option on couples' experiences**

Most studies in this review included men who underwent different treatment options (for example surgery and radiotherapy) and often analysed these different groups together. Such an approach makes it difficult to identify treatment-specific considerations that may be present for couples dealing with the treatment and consequences of prostate cancer.



## Literature Review

Several studies identified in this current review focused on a particular treatment option or specifically compared different treatment options. Four studies focused on couples following surgery (Mayes et al. 2009; Tsivian et al. 2009; Chambers et al. 2013; Wittmann et al. 2015), one study specifically focused on ADT (Walker and Robinson 2011a) and two studies compared ADT, with non-ADT (Hamilton et al. 2016; Van Dam et al. 2016). However, no studies were identified which specifically focused on couples undergoing external beam radiotherapy treatment.

Four studies (Mayes et al. 2009; Tsivian et al. 2009; Walker and Robinson 2011; Wittmann et al. 2015) specifically investigated couples' sexual recovery following prostate cancer treatment. Walker and Robinson (2011) investigated couples' sexual adjustment to the changes associated with ADT. In addition, Wittmann et al. (2015), Mayes et al. (2009) and Tsivian et al. (2009) investigated couples sexual recovery following prostatectomy and these studies will be further discussed in Section 3.7.1.

Hamilton et al. (2016) and van Dam et al. (2016) published a companion paper following an online survey in Canada to investigate the impact of ADT. Van Dam et al. (2016) investigated how ADT impacted the mood of prostate cancer patients and their partners and Hamilton et al. (2016) investigated how treatment type, patient mood and sexual function related to the dyadic adjustment from patients and partners perspectives. Hamilton et al. (2016) included 206 men diagnosed with prostate cancer (ADT n=50, non-ADT=156) and 66 partners (partners of men with ADT=33 and partners of men with non-ADT=33). The Profile of Mood States-Short Form (POMS) was used to assess mood (Shacham 1983). The Dyadic Adjustment Scale (DAS) was used to assess the nature of the relationship of the couples (Spanier 1976). The Expanded Prostate Cancer Index Composite (EPIC) was used to investigate the impact of prostate cancer and to

## Literature Review

assess aspects of sex life and sexual functioning (Wei et al. 2000). Hamilton et al. (2016) found that men on ADT reported a higher level of consensus with their spouse and higher levels of relationship functioning when compared to the men not on ADT. When looking at sexual functioning, men on ADT reported a worse sexual functioning and more discomfort when compared to men who were not on ADT. There was also a higher level of sexual bother reported by the men on ADT when compared to the men not on ADT. Specifically, a lack of desire and the inability to reach an orgasm were more recurrent in men who were on ADT. Similarly, partners of men on ADT reported worse sexual functioning when compared to the partners of men not on ADT. Men on ADT and their partners also reported experiencing a worse mood, which is likely to contribute to more relationship difficulties. Some similar findings were reported by van Dam et al. (2016) who noted that men on ADT scored significantly higher scores for fatigue and lower scores for vigour. Partners of men who were or were not on ADT reported similar patterns to the patients. However, some of the limitations noted in the study by Hamilton et al. (2016) and van Dam et al. (2016) is that the majority of participants were recruited as individuals and not as patient-partner dyads. Therefore, the findings of this study cannot compare directly how the score of one member of the couple may influence the other's adjustment following prostate cancer treatment.

Chambers et al. (2013) performed a cross-sectional survey of 189 prostate cancer patients, and their partners, who were scheduled or underwent surgery for localised prostate cancer. This study investigated socio-demographics variables, masculine self-esteem and social intimacy, psychological adjustment and QoL. Masculine self-esteem was measured with The Masculine Self-Esteem Scale (Clark et al. 2003) and the internal consistency of the scale was considered good, with a Cronbach's alpha of 0.88. Social intimacy was measured with The Miller Social Intimacy Scale (Miller and Lefcourt

## Literature Review

1982). This scale can be used to assess the current level of intimacy or closeness in participants' relationships and was reliable, with a Cronbach alpha of 0.90. Marital satisfaction was measured with the Revised Dyadic Adjustment Scale (Spanier 1976; Hunsley et al. 2001) and this scale also demonstrated excellent reliability ( $\alpha=0.82$ ). Anxiety and depression were assessed with the Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith 1983) and QoL was measured using The short Form 36 (SF-36) (Ware and Sherbourne 1992). Cancer distress was measured with The Impact of Event Scale – Revised (IES-R) (Weiss 2007). Chambers et al. (2013) noted that partners of men with prostate cancer had significant higher levels of anxiety; however, the levels of depression did not differ. Being younger, having a shorter length of time since diagnosis and having a lower masculine self-image were associated with greater anxiety and depression for the men with prostate cancer. Such findings indicate that the initial time period from the point of diagnosis up until treatment commences might be a particularly anxious time for the men. This could be related to their concerns about the severity of side effects and the outcomes following treatment. In contrast, being older and having a higher masculine self-image was associated with a better mental QoL. Such findings highlight the impact that age may have on the adjustment of couples following prostate cancer treatment as outlined in Section 3.5. In addition, masculine self-image may also be an important aspect to consider for couples dealing with the consequences of prostate cancer treatment. For the females, a longer period from patient diagnosis, greater urinary bother, less masculine self-esteem, and increased patient psychological distress were associated with greater depression. Chambers et al. (2013) suggested that there is an interaction between domain specific physical effects and the psychological response within the male-female dyad with distinct patterns for males and females. For men, a lower masculine self-esteem was strongly related to poorer mental health outcomes such as anxiety, depression, mental QoL and cancer-specific distress.

## Literature Review

In contrast, their partners' psychological distress and intimacy were not significant predictors of men's adjustment outcomes. Chambers et al. (2013) suggested that, for men, the driver for their distress appeared to be internal rather than relationship-focused. Chambers et al. (2013) specifically investigated men who had chosen or underwent prostatectomy. However, only 26% (n=48) underwent prostate surgery and therefore the anxiety levels may be associated with them undergoing such a major operation. Furthermore, this study reported baseline characteristics before a couple-based sexual intervention and therefore this could have resulted in more well-adjusted couples being included in this study.

Several other studies, which are presented below, have reported differences between treatments. For example, Grondhuis Palacios et al. (2018) investigated the sexual healthcare and satisfaction with treatment options in men and their partners following prostate cancer treatment. Men undergoing surgery reported the most complaints with erectile functioning (93.8%; n=60), followed by men treated with external beam radiotherapy treatment (77.9%; n=53). Furthermore, more than half of the partners (50.6%; n=81) reported difficulties in handling their altered situation with respect to sexuality. Some differences in the experiences of treatment-related side effects were also noted by Collaço et al. (2021), they investigated the experiences of younger men and their partners who had been affected by prostate cancer. Collaço et al. (2021) noted that after the completion of prostate cancer treatment, several men re-evaluated their work life due to the impact of treatment on their ability to work. In particular, it was noted that men who underwent external beam radiotherapy treatment or hormone treatment suffered from fatigue, and this led to some men reducing their working hours to facilitate this change.

Nelson et al. (2019) performed a qualitative longitudinal study and investigated the supportive care needs of couples in the first 12

## Literature Review

months following their cancer treatment. Nelson et al. (2019) reported that men opting for radical prostatectomy relied more on their partners for instrumental support (for example lifts to/from appointments, changing and dressing, and cooking meals) when compared with men who underwent external beam radiotherapy. Female partners reported being happy to provide this support and to take over, in the short term, household chores that had previously been shared with their partners.

Findings of the literature review revealed that most studies included patients undergoing a range of different prostate cancer treatment options, however the study end points were not evaluated according to the treatment received. Such an approach can make it difficult to identify treatment specific issues for couples dealing with prostate cancer, despite different prostate cancer treatments having a unique side effect profile which may generate treatment specific impacts on men and their partners. For example, men undergoing radical prostatectomy will experience the side effects of the treatment immediately after treatment and may therefore need more direct support from their spouse directly after treatment. However, men undergoing external beam radiotherapy treatment often present with delayed side effects and may require sustained support at a later stage. Furthermore, studies that investigate a particular treatment option often include men who underwent surgical removal of the prostate or hormone therapy, and no studies were identified in this literature review that specifically focused on external beam radiotherapy treatment.

### **3.7. IMPACT OF A PROSTATE CANCER TREATMENT ON THE LIFE AND RELATIONSHIP OF COUPLES**

Prostate cancer and its treatment can cause a range of side effects, these can have a negative impact on the life and relationship of couples. Couples may experience issues such as sexual dysfunction, communication difficulties, role reversal/changes and distress and

## Literature Review

these can adversely affect their relationship. Consequently, there is a growing interest in the study of the psychological concerns related to intimacy and interpersonal processes in couples affected by prostate cancer (Galbraith et al. 2011).

The literature review identified a range of quantitative and qualitative studies (see Appendix One) that investigated the impact of prostate cancer on the life and relationship of couples. Several specific areas were identified when synthesising the literature, these included sexual issues and recovery, couples' psychosocial needs and the impact on life and relationships. For this section, the main focus was to provide an in-depth overview of the impact of prostate cancer on the lives and relationships of couples through the review of largely qualitative research. However, other quantitative studies were included, where appropriate, to support the main narrative and/or provide further insight.

### 3.7.1. Sexual changes following prostate cancer treatment

Satisfaction with sexual life has been indicated as an important predictor of satisfaction in life for patients and their partners following prostate cancer treatment (Mallis et al. 2006; Guercio and Mehta 2018). The inability to perform sexually can lower an individual's sense of self-esteem and can lead to emotional and marital tension, this can have a negative impact on the relationship between men and their partners. For example, men who had erectile dysfunction due to prostate cancer treatment felt apprehensive about engaging in intimate contact with their partners, they feared that it might lead to an awkward and embarrassing sexual encounter (Wittmann et al. 2015). Besides erectile changes, changes in ejaculation have been observed by Mayes et al. (2009) and Tsivian et al. (2009) following prostate cancer treatment. Badr and Taylor (2009) found that both men and their partners experienced a high degree of sexual dysfunction

## Literature Review

following prostate cancer treatment and this was negatively associated with the psychological and marital adjustment.

O'Shaughnessy et al. (2013) performed a sequential exploratory mixed method approach involving initial focus groups and interviews with couples, this was followed by a web-based survey to investigate impaired sexual functioning in couples. The qualitative phase of the study was undertaken to explore the supportive care needs of men and their partners during the prostate cancer journey. Participants in the focus groups and couples involved in interviews were drawn from various backgrounds including rural and remote and included younger and older men in South Australia. However, no details were provided regarding their age, cancer treatment options or the period since diagnosis. Men participating in the focus groups indicated that sexual intimacy and mutual sexual expression were important for them, as these served as a way of expressing their love and affection within their relationship (O'Shaughnessy et al. 2013). In a secondary analysis of the interviews to further explore themes of love, hope and faith in this population, O'Shaughnessy et al. (2015) found that men viewed sex not only as a function or as a way of receiving pleasure but also as a way of showing their love and affection towards their partner. Making love was a key language for these men to express their love for their partner (O'Shaughnessy et al. 2015). The men in this study feared that a diminished sexual ability might negatively impact on their relationship with their partner. Some participants believed that the changes in sexuality and communication within the relationship had the potential to cause marriage breakdowns (O'Shaughnessy et al. 2015).

Given the high rates of erectile dysfunction and impact on sexual functioning, Beck et al. (2013) undertook qualitative interviews with 17 couples, firstly with couples and subsequently (from one week up to three months later) held individual interviews with the men and their spouses. Beck et al. (2013) investigated how some couples were able

## Literature Review

to maintain satisfying sexual intimacy and initially recruited couples who were able to restore satisfying sexual intimacy. This was then followed by couples who reported not being able to restore satisfying sexual intimacy. Beck et al. (2013) recognized that satisfied couples continued to work on their sexual recovery long enough to establish a new sexual relationship. Conversely, dissatisfied couples often waited for their sexual desire to arise before initiating sexual activity or waited for an invitation from their partner (Beck et al. 2013). Some similar results were identified by Walker and Robinson (2011) who investigated how couples adjust to the sexual changes associated with ADT. Walker and Robinson (2011) found three distinct patterns, with one group assuming that sex was no longer possible and accepting this loss. Another group was found to be struggling to either maintain satisfying sex or adapt to the loss of their sexual relationship. The third group struggled but found that they were satisfied with their sexual outcome. According to Walker and Robinson (2011), the use of assistive aids such as erectile oral medication or vacuum erection devices often removed their sexual appetite (Walker and Robinson 2011). Sexual appetite or sexual interest has also been indicated by Wittmann et al. (2014) to be perceived as critical for both men and partners in their sexual recovery following prostate cancer treatment. The use of assistive aids requires couples to plan ahead and eliminates the spontaneous nature of sexual intimacy, which they were used to prior to prostate cancer treatment.

Kelly et al. (2015) performed a descriptive qualitative study to investigate the impact of prostate cancer treatment on intimacy and sexual expression from the perspective of couples. This study recruited 18 participants from a variety of backgrounds, the men were all two years post-treatment in order to ensure that short-term treatment side effects were minimized and some adaptation to their new situation had occurred. Kelly et al. (2015) noted that the sexual functioning and the likely changes post-treatment of both patients and



## Literature Review

their partners were of interest. However, it appeared that for some couples it was challenging to discuss post-treatment sexual functioning with clinicians, as they apparently had not discussed sexual functioning well. Furthermore, couples felt that clinicians did not discuss sexual functioning fully enough before the treatment (Kelly et al. 2015) and partners were often excluded by clinicians when discussing treatment-related consequences. Couples indicated that limited opportunities were offered to discuss psychosexual needs (Kelly et al. 2015). Discussion with couples during consultation with clinicians was further explored by Forbat et al. (2012), who performed ethnographic observations during 60 consultations between clinicians, patients and partners. Similar results were noted to those identified by Kelly et al. (2015) in that, during consultations, sexual functioning was infrequently discussed in the clinic. Furthermore, despite the presence of the partner in nearly half of the consultations, the involvement of partners by the clinician tended to be minimal throughout the consultation. Consequently, based on the evidence reviewed, it appears that healthcare professionals may be unwilling to openly discuss sexual health issues during consultations. If such discussions with clinicians are limited, it could therefore indicate that these men and their partners may have unmet sexual health needs.

Grondhuis Palacios (2018) investigated the timing of discussions regarding sexual and relationship changes after prostate cancer treatment. Findings suggested that, during follow-up, little attention was paid to the impact of sexual dysfunction induced by prostate cancer treatment on the relationship of men and their partners. A consultation with a urologist or sexologist within three months of treatment, to discuss sexual and relationship issues, was considered as most preferable (Grondhuis Palacios et al. 2018).

### 3.7.2. Couples' psychosocial needs during and after prostate cancer treatment

It has been indicated that couples' psychosocial needs during and following treatment tend to go undetected and unmet (Chambers et al. 2013). These can include fear, distress, anxiety, depression, and low self-esteem. Men and their partners have to adapt to the changes caused by prostate cancer and several studies have reported psychosocial needs along the treatment trajectory which will be further outlined below.

Sanders et al. (2006) undertook focus groups with 10 couples to discuss their experiences regarding intimacy in their relationship. The spouses felt that their role had changed from being cared for, to a more active role of emotional caregiver. Although women reported that their 'relationship role' had changed, it is not clear whether they were prepared for their new role and whether they had any unmet needs to help them when dealing with their husband's diagnosis and treatment. Sanders (2006) noted that both men and their partners needed more information about how to manage surviving prostate cancer as a couple. In particular, couples noted that it would have been helpful to hear from other couples who had gone through the same experience.

An important resource that has been reported in the literature includes the use of prostate cancer support groups by men and their partners. For example, Oliffe et al. (2015) investigated the supportive care needs amongst couples attending support groups. This study included individual interviews with 15 couples who were asked about their relationship, supportive care needs and attendance at prostate cancer support groups. Findings highlighted the important role that a prostate cancer support group can offer to both men and their partners. Women in this study recognised that prostate cancer support groups would benefit their husbands, giving them the opportunity to connect with other men facing similar issues. Such support groups can provide a

## Literature Review

setting where men can meet other men and learn from each other's experiences (OliFFE et al. 2015). The support groups were seen to aid those men who were challenged by prostate cancer but committed to solving a shared problem. Besides the benefit for the men, an important aspect of attending support groups was to provide support for the women (OliFFE et al. 2015). Men who participated in this study recognised their limits in fully supporting and reassuring their wives, and suggested that women attending the support group might be better equipped to fill this void. Many women suggested that connecting with other women strengthened their ability to provide support to their husbands (OliFFE et al. 2015) and as such, support groups can therefore be a valuable tool in supporting men and their partners during and after prostate cancer treatment.

Collaço et al. (2021) provided some further details regarding the experiences of couples affected by prostate cancer. This qualitative study explored the experiences and needs of younger men (<65 years old) and their partners. Participants were recruited from a UK wide study 'Life After Prostate Cancer Diagnosis' (LAPDC) (Downing et al. 2016) where the men could indicate if they and their partner/spouse would be interested in participating in a telephone interview. This study employed a maximum variation sampling according to treatment type, ethnicity and survey response to ensure a wide range of experiences and participants were interviewed separately.

Collaço et al. (2021) noted that a couple's identity continuously evolves following prostate cancer treatment and that these couples need to be provided with the appropriate information, support and resources to aid them in their transition along the prostate cancer pathway. Collaço et al. (2021) identified communication as a key component in the successful adjustment of couples. The spouses were the communication initiators who prompted their husbands to discuss their feelings. However, communication was challenging

## Literature Review

between couples and outside of the dyad when talking about sexual functioning (Collaço et al. 2021). Collaço et al. (2021) reported that some couples noted changes in their social networks and community and observed that some of the side effects of prostate cancer treatment, such as fatigue, may have an impact on the ability to engage in hobbies and social activities. Furthermore, some couples found that friends were disinterested when discussing prostate cancer, a few mentioned that cancer is taboo in conversation with friends (Collaço et al. 2021).

### 3.7.3. Coping with prostate cancer as a couple

The literature revealed that prostate cancer treatment can cause a broad range of side effects that negatively affect couples' lives and relationships. Garos et al. (2007) found that couples affected by prostate cancer had greater levels of depression, poorer quality of sexual communication and more sexual dissatisfaction when compared to couples from the general population. The treatment of prostate cancer can therefore have a range of negative consequences. In addition, couples may use a variety of different coping strategies following a diagnosis of prostate cancer, these may positively or negatively impact upon their relationship. Regan et al. (2014) highlighted that the relationship satisfaction of couples was significantly associated with the use of supportive and negative coping strategies by patients and their spouses (Regan et al. 2014). Supportive coping strategies include responses where one spouse initiates emotional- or problem-based coping strategies to support the other spouse. Emotional-based coping strategies include behaviour that intends to support the partner in regulating his/her emotions and to ease the stress arousal (e.g., empathy, understanding, showing solidarity with partner). Problem-based coping strategies include support which is judged accommodating for the partner to resolve the practical part of the stressor (e.g., helping their partner to seek more information). Negative coping strategies refer to responses that are

## Literature Review

ambivalent, hostile or superficial, lacking in emotional warmth or empathy (Bodenmann 2005b).

The impact of prostate cancer on an intimate relationship was also highlighted by Berg et al. (2011) who noted that the negative stressful events caused by prostate cancer can spill over to the other spouse due to their close proximity and interactions. Prostate cancer and its treatment may cause numerous stressful events (for example continence or impotence) that not only affect the man but can negatively impact on the spouse (Berg et al. 2011). These findings highlight the dyadic nature of a prostate cancer diagnosis and treatment, and the importance of involving both members in the recovery process of prostate cancer.

Another aspect identified in the literature, which may influence the adjustment of couples to prostate cancer, is the use of different communication styles between couples. Three studies (Manne et al. 2010; Fagundes et al. 2012; Manne et al. 2015) investigated the communication process between couples. Fagundes et al. (2012) noted that if men or their partners had a higher level of avoidance, this often led to a negative effect, such as higher levels of distress for both. Therefore, avoidance or a lack of open communication could have a negative impact on couples. Similarly, Manne et al. (2015) noted that a lack of communication, such as holding back from sharing concerns, has been negatively associated with couples' intimacy and relationship satisfaction (Manne et al. 2015). When couples communicated more openly with each other both partners reported higher partner responsiveness and intimacy (Manne et al. 2018) and better psychological outcomes such as lower cancer-specific distress and depression (Manne et al. 2021).

Merz et al. (2011) investigated whether agreement, or disagreement, between patients and partners on the appraisal of prostate cancer side effects had an impact on their QoL and relationship. Merz et al. (2011)

## Literature Review

suggested that dyadic disagreement is associated with a worse health-related QoL in couples facing prostate cancer. These findings therefore not only highlight the dyadic nature of prostate cancer, but also indicate that the appraisal of side effects from men and/or their partners can affect the couples' QoL.

These findings highlight the importance of including men and their partners in the information provision process, this was further explored by Docherty et al. (2007) who investigated the experiences of patients and spouses throughout their prostate cancer pathway. Docherty et al. (2007) conducted focus groups with men and their partners, the participants were recruited from prostate cancer support groups. Docherty et al. (2007) revealed that there was a lack of awareness of potential treatments or side effects. Furthermore, Docherty et al. (2007) noted that spouses often adopted the role of information seeker for their husbands and that men increased their participation in the treatment decision making after they had joined a prostate cancer support group. Although this study provides further insight into the experience of couples throughout the cancer journey, couples in this study were recruited from a prostate cancer support group. Consequently, couples may be more willing to seek and receive support from others, this could have had an impact on the findings of this study.

Nelson et al. (2019) performed a longitudinal qualitative study to explore how men and their partners utilise social support in the first 12 months following a localised prostate cancer diagnosis. This study recruited 18 couples from two outpatient clinics in the UK. Nelson et al. (2019) revealed that support networks for couples became smaller as time progressed and that prostate cancer support groups were an important source of support for the couples (Nelson et al. 2019). The partners in this study also acknowledged that they often provided higher levels of support than they received back from their husbands,

## Literature Review

which may be psychologically demanding. In addition, Nelson et al. (2019) found that stigma had an important role on the men's disclosure of their prostate cancer diagnosis to others. A lack of disclosure of the prostate diagnosis by the men, due to perceived stigma, may limit support from other friends and relatives which could result in partners being the primary provider of social support. Furthermore, Wood et al. (2019) indicated that perceived cancer stigma by the men is negatively associated with the QoL scores of men and their partners, but not their relationship satisfaction (Wood et al. 2019).

The literature reviewed indicated that the way couples integrated the changes caused by a prostate cancer diagnosis and related treatment side effects may vary, according to the socio-cultural background in which they live. For example, Bamidele et al. (2019) investigated the psychosocial consequences of prostate cancer amongst black African and Black Caribbean men and their partners in Northern Ireland. Bamidele et al. (2019) indicated how some men 'took personal control' of their disease and minimally involved their wives in the recovery process. Some of the men in this study did not publicly disclose their diagnosis and restricted their wives from public disclosure as they perceived it to be a sign of weakness and vulnerability that was not consistent with their masculine identity (Bamidele et al. 2019). Bamidele et al. (2019) suggested that cultural values for Black African and Black Caribbean men in the UK encourage them to take responsibility for themselves and others, this may explain their preference for a self-reliant approach in their management of prostate cancer. The motivation for this appears to be that these men do not want to share the cancer burden with their partners. Bamidele et al. (2019) recognise a 'hierarchy of power' between the dominant men and their subservient spouses who mostly act from a supportive and accepting position. These values can be seen in contrast to the more common Western type of relationship, which can be viewed as a more equal distribution of power between man and spouse (Rabin 2002).

## Literature Review

Furthermore, since prostate cancer is gender-specific, cultural values and beliefs on gender role expectation may have a greater impact on the adjustment of couples to prostate cancer. However, results from this literature review revealed that most studies are from the UK, the USA, Canada and Australia, which potentially limits the understanding of couples coping with prostate cancer to these specific areas and social and cultural backgrounds.

### **3.8. SUMMARY**

This literature review identified a body of mixed study designs that focused on men and their spouses throughout the prostate cancer journey. However, the review of the literature revealed several areas that required further attention. Specifically, studies designed to evaluate impact following prostate cancer treatment should consider that the greatest physical and psychological consequences occur within the first two years following the completion of treatment. However, qualitative studies that specifically focus on this time period are limited, with most studies often including men who had completed prostate cancer treatment over a long time period, sometimes more than 10 years previously. As couples progress from active treatment into post-treatment 'survivorship', their needs are likely to change over time and therefore, time since completion of treatment will have an impact on the findings of studies. Another factor that could influence the experience of couples is the age of the men at the time of diagnosis and treatment. However, most studies identified in this review do not focus on specific age groups but include all age ranges. Only a few studies focused on specific age groups, typically investigating younger men (<65 years) (e.g. Collaço et al. 2021). No studies were identified that specifically focused on men in their mid-60s or early 70s, although this is often the most common age group to receive active treatment for prostate cancer. In addition, at this age, men and their partner typically enter a transitional status in life as retirement occurs, and



## Literature Review

therefore they may have different needs when compared to younger or older couples.

Although a range of treatment options are available with their specific issues and needs, most studies include couples who underwent a range of different treatment options. This therefore limits understanding of treatment-specific issues and/or needs that may be present. Only a few studies focused on a particular treatment option and these focused on surgery or hormonal treatment. No studies were identified which focussed on external beam radiotherapy treatment.

Although couples' experiences of prostate cancer treatment have been investigated intensively, such experiences may differ between countries. The majority of studies identified in this review were conducted in a small number of countries with a relatively similar social, economic and cultural background, this limits the understanding of couples' experiences to these specific settings. No studies were identified in Malta which is considered to have a different social, economic and cultural setting, this may influence the experiences of couples following treatment for prostate cancer.

### **3.9. CONCLUSION**

This chapter presented a review of key relevant literature and identified gaps in the existing evidence base, these are further explored in this study. The following chapter presents the methodology and methods adopted.

## CHAPTER 4. METHODOLOGY

### 4.1. INTRODUCTION

This chapter presents and discusses the methodology adopted for this study to better understand the experiences of men and their spouses during and after external beam radiotherapy treatment for prostate cancer in Malta. The chapter begins by outlining the primary aim and objectives used for this study. This is followed by an overview of the underlying philosophical assumptions and the impact of this consideration on the data generation process. Subsequently, the methodology and methods used to gather and analyse the data are outlined. The last section of this chapter describes the ethical and governance considerations observed for this study.

### 4.2. RESEARCH AIM AND QUESTIONS

The aim of this research was to explore the experiences of men (aged 64-74 years) and their partners in the first two years following external beam radiotherapy treatment for prostate cancer in Malta. The main research question for this study was:

- *What are the experiences of men (aged 64-74 years) and their partners in the first two years following external beam radiotherapy treatment for prostate cancer in Malta?*

To answer the research question several objectives were formulated, based on the literature review, and these covered key phases of the cancer pathway. The objectives of this study were to explore:

## Methodology

- Experiences of the healthcare system for men and their spouses before commencing external beam radiotherapy treatment.
- Experiences of undergoing external beam radiotherapy treatment for prostate cancer for men and their spouses.
- Men and their spouses' experiences of the follow-up care after the completion of external beam radiotherapy treatment for prostate cancer.
- The impact of an external beam radiotherapy treatment for prostate cancer on the life and relationship of men and their spouses.

### **4.3. PHILOSOPHICAL ASSUMPTIONS**

All research is guided by common beliefs or principles that shape the way in which the researcher sees the world and acts in it. Huff (2008) indicates the importance of philosophy in research and how this can be used to formulate the research problem and research question and how we subsequently seek information to answer the question. These principles combine beliefs about ontology, epistemology and methodology (Guba and Lincoln 2005).

Epistemology refers to the nature and development of knowledge and ontology refers to the beliefs about concept of reality. In the positivist model it is assumed that "truth" can be objectively measured and is free from opinion and personal bias (Carey 1989). Positivism may be applied to the social world on the assumption that:

*"the social world can be studied in the same way as the natural world, that there is a method for studying the social world that is value free, and that explanations of a causal nature can be provided" (Mertens 2005, p.8).*

A positivist model assumes that there are 'social facts' that exist independently of the activities of both participant and researcher

## Methodology

(Guba and Lincoln, 2005). Positivists largely aim to test a theory or describe an experience:

*"through observation and measurement in order to predict and control forces that surround us" (O'Leary 2004, p.5).*

The use of the positivist paradigm has contributed to the significant growth in scientific knowledge in healthcare, producing large numbers of replicated facts about health, illness and treatments that can be analysed (Dash et al. 2019).

At the other end of the ontological spectrum is the naturalistic approach to research, commonly referred to as the interpretivist position (Schwandt, 2007). Interpretivism does not assume that there is a single truth that can be measured objectively, but instead assumes that there are multiple interpretations to view the world. Interpretivism accepts multiple viewpoints of different individuals from different groups. According to Willis et al. (2007) the idea of multiple perspectives arises from the belief that external reality is variable. Willis et al. (2007) indicates that "different people and different groups have different perceptions of the world" (p.194). The acceptance of multiple perspectives in interpretivism often leads to a more comprehensive understanding of phenomena (Morehouse 2012). This will significantly facilitate researchers when they need 'in-depth' and 'insight' information from population rather than purely numerical data, which might also involve some form of statistics.

Positivism and interpretivism are two mutually exclusive paradigms about the nature and source of knowledge. However, while some researchers may be more naturally, closely aligned to a particular paradigm, it is possible that some may alter their philosophical assumption over time and move to a new position along the continuum. For example, such researchers may consider a more pragmatic approach to research, which accepts that there can, where

## Methodology

appropriate, be a single or multiple realities that are open to related inquiry. According to pragmatist position, knowledge of the world can be obtained by observation, experience and experimentation (Moses and Knutsen 2007). Where appropriately, pragmatics can therefore combine both positivist and interpretivism position within a single study according to the nature of their research question.

As the aim of this study was to explore the experience of prostate cancer treatment from the perspectives of patients and their spouses in Malta, an interpretive position was adopted. An interpretivist position enabled me to capture multiple perspectives from couples living with and affected by prostate cancer treatment in Malta. As different people may have different experiences and therefore, also, views, an interpretivism position can capture their subjective meaning and, consequently, I looked for the complexity of views, rather than attempting to narrow the meanings into a few categories or ideas. Such an approach allowed me to investigate the perspective of each individual and to understand their construction of reality. Denzin and Lincoln (2005) consider the philosophical assumption as key premises that are incorporated into interpretive frameworks.

Having established the appropriateness of an interpretivism position for this study, the next section provides an overview of the methodology adopted for this study.

### **4.4. STUDY DESIGN**

The aim of this research was to explore the experiences of men (aged 64-74 years) and their partners in the first two years following external beam radiotherapy treatment for prostate cancer in Malta. A qualitative descriptive, cross-sectional study design was adopted. A qualitative descriptive approach was considered the most appropriate methodology to meet the aims and objectives of this study. A qualitative descriptive approach seeks to discover and understand a

## Methodology

phenomena, a process, or the perspective and world view of the people involved (Caelli et al. 2003). A descriptive qualitative approach could provide an in-depth understanding of the phenomenon under investigation and moves beyond the literal description of the data and attempts to interpret the findings without moving too far from that literal description (Sandelowski 2010).

### **4.5. QUALITATIVE DESCRIPTIVE METHODOLOGY**

Methodology has been defined as ‘a general approach to studying a research topic’ (Mason 2002 p19). A methodology refers to the choices that are made about studying the research topic; methods of data gathering, forms of data analysis in planning and executing a study. Therefore, a methodology defines how one goes about studying a phenomenon. Methodological assumptions consider how researchers approach findings out of what they believe can be known (Denzin and Lincoln 2005).

As this study explored the experiences of men and their spouses in the first two years of completion of prostate cancer treatment, a qualitative descriptive approach was adopted. Within qualitative descriptive research participants are asked to describe a phenomena in their own words, so that the researcher has a better understanding of their experiences, which in healthcare research might then also be used to help improve practice outcomes and/or improve negative health consequences (Sullivan-Bolyai et al. 2005). Qualitative description provides rich information regarding health related concerns and issues that are grounded in both environmental and cultural context (Sandelowski 2000). As this current study investigated the experiences of men and their partners in the first two years following external beam radiotherapy treatment, a descriptive qualitative approach therefore enabled me to provide a rich description of their experiences.

## Methodology

Qualitative descriptive designs have been used extensively in nursing and healthcare research (Doyle et al. 2020). Sandelowski (2000) was one of the first authors who promoted the use of qualitative description as a well-developed methodology. According to Sandelowski, researchers using this approach:

*“Stay closer to their data and to the surface of words and events”*

(Sandelowski (2000) p. 336)

Researchers who use qualitative description may choose to use the lens of an associated interpretive theory or conceptual framework to guide their studies, but they are prepared to alter that framework as necessary during the course of the study (Sandelowski 2010). A qualitative descriptive approach requires the researcher to adopt a flexible approach that is inductive and dynamic but does not transform the data beyond recognition from the phenomena being studied (Sandelowski 2010). A qualitative descriptive design recognises the subjective nature of the problem, the different experiences participants have had and will present the findings in a way that reflects or closely resembles the terminology used in the initial research question and used by the study participants (Bradshaw et al. 2017).

The critique against the use of a qualitative descriptive design is that unlike some of the other qualitative approaches, such as phenomenology, it is not necessarily theory driven or orientated (Neergaard et al. 2009). However, a qualitative descriptive approach requires that the researcher considers if and how a theory will inform their study and to what extent. Within this approach, researchers should be flexible and may change their theoretical frameworks, which are thought to be relevant and inform individual research, and therefore this can be considered a strength of utilising this approach (Sandelowski 2010). Another critique for this approach is that there is

## Methodology

limited methodological guidance about this type of design in related literature (Doyle et al. 2020). Although the lack of guidance may be seen as a critique, researchers using this approach can recognise and incorporate uncertainty about the phenomena being studied and apply specific research methods that are suitable. For example, such an approach permits the use of one or more different type of inquiry, this is essential when exploring different realities and subjective experiences in practice (Long et al. 2018).

### **4.6. CHOOSING A QUALITATIVE DESCRIPTIVE METHODOLOGY**

During the design of this study, I considered several other potential qualitative approaches such as ethnography, phenomenology, and a case study design. An ethnographic approach is often used to portray a culture and such designs typically involve the observation of a specific cultural group, often for an extended period of time (Creswell 2012). In such research, the researcher is often involved in everyday activities of the participant group and detailed data are collected about participants' worlds to provide an in-depth understanding of their views (Denscombe 2017). As the aim of this study was not to observe the couples over a period of time, such a design was not deemed to be the most suitable. Within phenomenology the two main approaches which guide most studies are descriptive and interpretive phenomenology. Edmund Husserl is considered to be the founder of phenomenology and the descriptive approach. Husserl (1970) defined phenomenology as 'the science of essence of consciousness' and focuses on the meaning of lived experiences (Husserl 1970). According to Husserl (2001), researchers are able to successfully abandon their own lived reality and describe the phenomenon from an objective stance (Husserl 2001). However, since I have been closely involved in the delivery of care to patients undergoing external beam radiotherapy treatment, I felt that such an objective stance would be difficult to maintain and/or achieve during the study and therefore such



## Methodology

an approach was not deemed appropriate. Conversely, Hermeneutic phenomenology goes beyond knowledge or core concepts and essence and Heidegger (1962) emphasizes that individuals cannot meaningfully abstract themselves from various contexts that influence their choice and give meaning to lived experiences (Heidegger 1962). Interpretive phenomenology is most useful when the goal is to interpret contextualized human experiences. Such interpretations are a blend of meanings and understandings articulated by the researcher and the participants. Hermeneutic phenomenology requires the researcher to reflect on his or her past experiences and preconceptions and biases before they start their inquiry. Although an interpretive phenomenology approach could have been adopted for this study such an approach places the essence of meaning of lived experiences, as reflected in concrete detailed examples of the lifeworld, in the forefront of the research process (Norlyk and Harder 2010). Such an approach therefore seeks to describe the meaning of living through an experience such a prostate cancer diagnosis and treatment. However, a descriptive qualitative approach focuses on an in-depth understanding of a health-related experience which includes the cultural contextual factors that shape participants' experiences (Sullivan-Bolyai et al. 2005). A descriptive qualitative approach therefore allowed me to look beyond the lived experiences of men and their spouses and look at social and cultural factors and barriers in health care, from the perspective of the recipient of care that can be particularly useful for practice.

Another research approach I considered included the use of case study. Case studies are designed to suit the case and research question. Case study research is an investigation and analysis of a single or collective case(s), intended to capture the complexity of the object of study (Stake 1995). Case studies revolve around 'cases' which are highly specific and only relate to a particular context or a few units, this may make it more difficult to transfer the findings to other

## Methodology

settings (Yin 2003). Although the scope of this research was not to generalise the findings, certain elements may be transferable to other settings or populations. A case study approach requires the in-depth exploration of a few units with multiple variables, and this may therefore limit a broader understanding from a particular phenomenon. In addition, the focus in case study research is on a particular unit which can be an individual, a dyad, group, or organisation and is suitable to understand the interaction between a specific concept and a phenomena (Krusenvik 2016). As this current study investigated the experiences of men and their spouses in the first two years following prostate cancer treatment, a qualitative descriptive approach allowed me to gain a deeper understanding of the phenomena under investigation. Furthermore, such an approach allowed me to provide analysis and interpretation of the findings that remain close to the data and therefore representative of the responses of the participants.

### **4.7. METHODS FOR DATA GENERATION**

This section examines the methods that were employed to undertake this study. Firstly, negotiating access to the participants, the recruitment process and sampling techniques used in the study will be outlined. The methods used to generate and analyse data are then presented before the epistemological perspective is acknowledged. Finally, credibility, dependability, transferability, and confirmability and how they were promoted in this research are explored.

#### **4.7.1. Negotiating access and participants recruitment**

Accessing an organisation to conduct research can be complex and usually involves either a formal process of entering an organisation, followed by an informal (or possible formal) process, whereby the researcher becomes known to the relevant 'gatekeepers'. While the term 'gatekeeper' can be used in a number of different ways,

## Methodology

gatekeepers within the research process are typically described as individuals, groups, and/or organizations that act as intermediaries between researchers and participants (Laine, 2000). There is one oncology hospital in Malta which offers external beam radiotherapy treatment and therefore this hospital was approached for access to prospective participants. I had previously worked as a radiographer in the radiotherapy department and therefore I was familiar with the clinical staff and internal procedures and processes. Prior to the commencement of this study, I had informally approached two clinical oncologists and two radiographers involved in the care of prostate cancer patients to explain my study, they agreed to assist in the recruitment of participants and act as 'gatekeepers' in the recruitment process, subject to relevant approvals. I subsequently kept in regular contact with the oncologists and radiographers throughout the duration of fieldwork, updating them regarding my progress with recruitment and data collection to maintain a good working relationship.

### 4.7.2. Recruitment and sampling

The recruitment of participants took place in an outpatient department of the oncology hospital in Malta. During their follow-up clinic two clinical oncologists, who acted as the gatekeepers, were asked to identify and initially approach eligible candidates for this study using the agreed inclusion/exclusion criteria (discussed in more detail in Section 4.7.2.2). During these clinics a large number of patients were seen by both oncologists, this could have made it difficult for them to recruit participants to the study as they may have been too busy. In fact, there is evidence to suggest that recruitment can be problematic in busy clinic settings due to a lack of time, resources and disruption of the individual or organisation (Din and Cullingford 2004; Munro et al. 2005). Negotiating access is based on building relationships with gatekeepers, this is an ill-defined, unpredictable, uncontrollable process (Feldman et al. 2003). Although I established a good rapport with the gatekeepers, as I have worked with them for several years

## Methodology

prior to this study, only one couple were recruited in the first three-months of data collection.

The initial challenges with recruitment were discussed during a supervisory meeting and a new recruitment process was proposed. The new recruitment process involved the identification of potential participants, using the same inclusion/exclusion criteria (See Section 4.7.2.2) from the hospital IT system, by two radiographers who had informally agreed to act as gatekeepers subject to the relevant approvals. The use of the hospital IT system made the identification process faster and reduced the likelihood of the omission of potential candidates from the outpatient department clinic lists. Permission to change the recruitment process was requested and obtained from the Research and Ethics Committee in Malta and Cardiff (Appendix two). The changes in the recruitment process resulted in the identification and recruitment of eligible participants to conduct the study.

### 4.7.2.1. Sampling technique

Several sampling techniques are commonly used in qualitative research including convenience and purposive sampling. Convenience sampling relies on chance of opportunity or social networks to generate a sample (Marshall, 1996). Although this can be the least costly in terms of effort, money or time, this type of sampling may result in poor quality data which could lack intellectual credibility (Marshall, 1996).

For this study a purposive sampling method was adopted. Denzin and Lincoln (2005) indicate that purposive sampling allows the researcher to seek groups, individuals, and settings where the process being studied is most likely to occur. In purposive sampling individuals are deliberately selected with an explicit purpose in mind, namely, to address the research question, as they have direct experience of the topic area and are therefore a rich source of data in relation to this (Marshall, 1996). Several features were identified in the literature

## Methodology

review which could have influenced the experience of candidate participants, including treatment options prescribed, age at diagnosis and the time period following primary treatment (Galbraith et al. 2008; Walker and Robinson 2010; Sousa et al. 2012).

The age group included in this study was adopted from a qualitative study that grouped men with prostate cancer and their partners according to their life stage cohort (Harden et al. 2006). Harden et al. (2006) examined the experience of men with prostate cancer and their partners according to their life cycle cohort and grouped couples in three age categories: 50-64 (late middle age), 65-74 (young-old) and 75-84 (old-old). The different age groups were based on a life span perspective, which suggest that adults experience a series of gains and losses across all ages of the life span (Baltes 1987)

Harden et al. (2006) defined people 65-74 years of age as 'young-old' to identify a cohort moving through a transitional stage, as individuals typically enter retirement and therefore a transitional status in their life. However, as the retirement age varies between countries, the age bracket was adapted in my study to make it more suitable in the local setting. In Malta, individuals born between 1952 and 1955 can retire at the age of 62, between 1956 and 1958 at the age of 63 and individuals born between 1959 and 1961 can retire at 64 years of age (Department of Social Security [Malta] 2022). In fact, at the time of data collection (January – December 2019) individuals could have entered retirement before 65 years of age. Therefore, the age group was expanded to also include men at 64 years of age as they could have entered into the retirement phase, particularly if they were unwell due to their condition.

### 4.7.2.2. Recruitment process

In accordance with Research Ethics Committee (REC) approval, participants were identified, approached, and recruited onto the study by clinical gatekeepers using a formulated inclusion/exclusion

## Methodology

criterion. This was based on key issues highlighted in the literature review and in accordance with the research question.

The following inclusion criteria were therefore formulated for the male patient participants:

- Have a confirmed histological diagnosis of localised prostate cancer
- Have consented to undergo external beam radiotherapy treatment
- Be married and/or cohabiting with a partner / significant other (regardless of gender)
- Able to communicate in English
- Aged between 64 -74 years at time of radiotherapy treatment
- Have completed external beam radiotherapy treatment in the last six - 24 months

As this study investigated the impact on couples, men had to be married and/or cohabiting with a partner or significant other (regardless of gender). The partner needed to be able to communicate in English and provide informed consent. However, no further criteria were set for partners as to not further limit the potential number of relevant participants.

The clinical gatekeepers identified potential participants from the hospital IT system and contacted them via a phone call. Willing participants were then sent an information pack. This information pack included a REC approved participant information sheet and an expression of interest sheet (Appendix two). Prospective participants were required to complete and return these to the researcher (using a free post envelope) if they were interested in taking part in the study. This was then followed by a telephone call from the researcher to provide additional information, screen for eligibility and answer any further questions about the study. A mutually convenient meeting was

## Methodology

then agreed with potential participants, this was either in their home or at the local oncology hospital. Written and verbal consent was obtained from all participants prior to each interview. A total of 52 men were contacted by the gatekeepers and 14 interviews were conducted. The reason for refusal to participate varied, the two most common reasons given to the gatekeepers were either lack of interest in the study (n=20) or unable to conduct the interview in English (n=12).

### 4.7.3. Data generation methods: in-depth interviews

In qualitative research a variety of data collection methods can be used, such as participant observation, focus groups and interviews (Silverman, 2013). For this study, data were collected using interviews and the following section provides a detailed discussion and justification of the method used.

Interviewing can be seen as an interactive method in which mutual understanding occurs between those involved in the interview process. According to Fontana and Frey, (2005) an interview can be seen as a “contextually bound and mutually created story” produced by interviewer and interviewee(s) (Fontana and Frey 2005, p696). Interviews enabled me to focus on the participants’ perspectives of what is important to them, thereby potentially highlighting issues that I might not have previously considered. Interviews can be used to explore the views, experiences and beliefs of individuals or groups on specific issues (Kvale 1996).

Interviews have been indicated to potentially produce more detail than focus groups, and offer more insight into a participant’s personal thoughts, feelings, and world view (Knodel 1995; Morgan 1998). In addition, there is some evidence to suggest that sensitive topics may be better addressed in an interview, as some participants may be hesitant to disclose sensitive topics in a group environment (Wight, 1994; Kaplowitz 2000). As this study investigated personal

## Methodology

experiences of couples following prostate cancer it was anticipated that sensitive topics may be discussed, such as sexual issues amongst couples following prostate cancer treatment, the use of interviews was therefore selected as the most appropriate data collection method. It was also congruent with the methodology used to conduct the study.

### 4.7.3.1. Semi-structured approach

There is a range of interview types and techniques which can be used to suit the purpose of the study being undertaken, such as unstructured, semi-structured or structured interviews. For this study, a semi-structured approach was adopted, and this will be discussed in more detail in the following section.

Specific questions, used without flexibility, as in the case of a structured approach, often lack sensitivity in understanding how participants interpret and understand the context of the phenomenon under investigation (Mason 2002). It has also been recognised that an unstructured approach may be particularly difficult for a novice researcher, who may not be equipped with the skills to tap into elements of the interview that may be unconscious to the respondent but important to the researcher (Charmaz 2014). Interviews generally need a degree of structure to enable the researcher to follow leads in responses and decrease the potential influence of preconceived ideas. Mason (2002), argues that it is not possible for an interview to be completely unstructured, so that the researcher can freely associate questioning and response, because the assumptions of the interviewer and interviewee will probably force a framework on the interview process (Mason 2002). Semi-structured interviews are mainly used when a researcher wants to gather rich data without the constraints of an extensive, specific set of questions (Kvale 2007). Such an interview approach therefore could provide guidance on the topic areas to be covered and the flexibility required to discover new insights (Robson



## Methodology

2011). For these reasons a semi-structured interview approach was used for this study.

An interview schedule was developed based on the pertinent issues identified in the reviewed literature and in relation to the research question, this was also used to guide the interview schedule and explore associated issues. The interviews started with an easy context-setting question before progressing to questions about more difficult, sensitive, or in-depth areas (See Appendix three). As this study employed a semi-structured approach, the interview guide included a short list of key questions that were supplemented, where appropriate, by follow-up and/or further probing questions dependent on the participant responses (Kallio et al. 2016). The interview schedule included 'grand tour questions' (DeJonckheere and Vaughn 2019), core questions, planned follow up questions and unplanned follow up questions. Table 2 provides examples of the different type of questions used for the interviews.

## Methodology

Table 2: Interview questions and examples of follow up questions

<b>Type of question: Grand tour</b>		
<b>Definition</b>	<b>Purpose</b>	<b>Example(s) (some of which were based on participants' responses)</b>
General questions related to the context of the research.	<ul style="list-style-type: none"> <li>- Initiate the interview</li> <li>- To let participants talk about their experience</li> </ul>	How would you describe your experience leading to the initial prostate cancer diagnosis?
<b>Type of question: Core questions</b>		
<b>Definition</b>	<b>Purpose</b>	<b>Example(s) (some of which were based on participants' responses)</b>
Questions that directly related to the information the researcher wants to know	<ul style="list-style-type: none"> <li>- Answer the research question</li> <li>- Help participants talk openly about the topic in an explorative way</li> <li>- Asked to all participants</li> </ul>	How would you describe the impact of prostate cancer treatment?
<b>Type of question: Planned follow up questions</b>		
<b>Definition</b>	<b>Purpose</b>	<b>Example(s) (some of which were based on participants' responses)</b>

## Methodology

<b>Specific questions that ask for more detail about aspects of the core question</b>	<ul style="list-style-type: none"> <li>- To obtain greater detail about responses</li> <li>- Asked depending on the participants responses</li> </ul>	(If appropriate) It sounds that you have experienced [insert side effect] as a result of the treatment. How did this affect you and your partner?
<b>Type of question: Unplanned follow up questions</b>		
<b>Definition</b>	<b>Purpose</b>	<b>Example(s) (some of which were based on participants' responses)</b>
Questions that arise during the interview based on participant responses	<ul style="list-style-type: none"> <li>- Answer particular aspects of the participant response</li> <li>- Obtain greater detail about responses</li> </ul>	You mentioned that you were a bit depressed following the diagnosis. Can you tell me a bit more about this?

As this study investigated couples' experiences, careful consideration was given as to whether couples were interviewed together or separately, as discussed in the next section.

### 4.7.3.2. Couples or individual interviews

To better understand the experience of couples, a decision was taken as to whether to conduct interviews with the couples separately or jointly. This section provides an overview of the advantages and disadvantages of these approaches and the approach adopted for this study.

## Methodology

When partners are interviewed together they commonly represent themselves not just as individuals, but also as concurrent participants in a relationship (Morris, 2001). In couples' interviews partners can corroborate or supplement each other's stories. The couple can probe, correct, challenge, or introduce fresh themes for discussion which could not be identified during individual interviews. In joint interviews partners can jointly negotiate and construct their narrative (Racher 2003). It has been suggested that joint interviews enable individuals to blend their perspectives and present themselves as a couple (Hertz 1995). Couples' interviews are often referred to as dyadic interviews. In dyadic interviews two participants interact in response to open-ended interview questions (Morgan et al. 2013).

Some advantages of dyadic interviews include the opportunity for the researcher to observe the couples' interactions, dynamics and negotiations. When couples converse, greater detail and contrast may become evident as elaborations, corroborations, and disagreements emerge, providing a fuller picture and richer data than a single perspective could afford (Sohier 1995; Valentine 1999). However some disadvantages have been suggested, for example couples may not speak openly and frankly in the presence of their partner but instead may adjust their answers to their partners' expectations (Aquilino 1993; Taylor and de Vocht 2011). This could lead to individuals avoiding discussing certain issues that could upset their partner.

During individual interviews participants can express their individual views or preferences, although this does not mean that the individual will be discussing something without their partner's consent. It does however recognise that a person's experiences may not be identical to their partners. The presence of one partner could impact on the behaviour of the other (and vice versa) and therefore joint interviews could influence participants' responses and/or the interpretation of the

## Methodology

experiences that are described. Whether both partners are interviewed together or separately, the interview is likely to be different. As Parahoo (2008) explained, if one takes the view that couples co-create meanings, then the researcher is “faced with the potential of three different perspectives: those of both individuals on their own and of the couple as a unit” (Parahoo, 2008 p. 275).

It has been recognised that some topics are inherently more dyadic than individual, such as when the topic under investigation is a shared experience by the members of a dyad, such as childbirth, end of life care or the adjustment to an illness (Eisikovits and Koren 2010). As this study investigated the experience of men and their partners, dyadic interviews with couples were selected to capture their shared meaning.

Interviews of this type enable a special form of relationship, where the interviewer and interviewee(s) converse about important and often personal topics. The interviewer must therefore build rapport quickly by listening attentively and respectfully to the information shared by the interviewee(s) (Spradley 2016).

### 4.7.3.3. Dyadic interview in practice

The use of dyadic interviews allowed the couples to probe and engage each other during the interview process. In fact, it was noted that the couples often facilitated each other as can be observed from the conversation below.

*GvD: ‘How would you describe your experience of undergoing the radiotherapy treatment?’*

*P3: ‘The radiotherapy was a very positive experience in inverted comma’s’*

## Methodology

*FO3: 'The preparation for it wasn't very pleasant you had to put that thing the enema'*

*P3: 'No no I forgot about it alright yes that was something I hated, but thereafter the treatment that I received and the staff it was ok.'*

*FO3: 'even before around 2 months before they told him try to eliminate coffee and tea and fizzy drinks and increase your water intake and he is a tea addict. He did it but....'*

*P3: 'That was another thing I forgot these things because they passed but yes that was another, I went for 3 months it was drinking not more than one tea or one coffee a day that was horrendous and drinking water at least every hour, 200 millilitres of water. I used to do it scrupulously and had the alarm on my mobile because I don't like to drink water.'*

The use of dyadic or couple interviews therefore provided opportunities for participants to interact and negotiate with each other, this cannot be obtained from individual interviews. However, couples' dynamics and interactions were often non-verbal, and it was perceived to be difficult to record these, as the interviews were audio recorded. In particular, it was noted that the body language of the partner sometimes suggested that the other person did not agree with their account or perspective. For example, I noted that partners rolled their eyes or shook their head which could perhaps indicate disagreement with each other. During these instances I engaged the other participant to explore their views or asked if they agreed or disagreed with what their partner was saying. Such an approach could lead to disagreement or a discussion between the couple and, when managed appropriately, can provide richer data that probably cannot be

## Methodology

achieved in individual interviews. Discussions and disagreements were also identified in this study, these can often provide a better understanding of the couple's views and perspectives, as can be observed from the conversation below. This particular couple had a disagreement regarding the disclosure of the prostate cancer diagnosis to more distant friends and relatives:

*P02: 'No nobody knows about it just me and the kids even at work only two people know about it'*

*GvD: 'Why didn 't you inform other people?'*

*SO2: 'I told my sister and even my friend'*

*SO2: 'and even your friends at work you told them'*

*P02: 'The friends at work, two of them the one's that are close you know. I can trust him and he can trust me but otherwise the rest...'*

*SO2: 'Why why shouldn't you. If you come in the hospital everyone will see you. They will see you come here and they will know that you will have something as otherwise you wouldn't be coming here is it?'*

*P02: 'For me personal I didn't go out and tell him this that and the other one. I told the people that are really concerned what I needed them to know and that was it.'*

*SO2: 'like if I didn't talk to my friends about it I wouldn't know that their husbands went through it and they are ok.'*

During some interviews it was noted that one partner did more talking than the other. This has also been identified by Hertz (1995), who argued that when a couple are interviewed together it is often one

## Methodology

partner who does far more talking than the other and therefore such scenarios can provide a more simplified official account rather than the complex, multi-account that joint interviews are often credited with (Hertz, 1995). Consequently, when discussions were largely led by one person, to ensure that the other partner was sufficiently included in the dyadic interview, specific or probing questions were directed to them such as: 'So now that your partner discussed this, how would you describe this?' Although this approach allowed the other participant to be more engaged in the interview, it was not always possible to get a balanced contribution from both participants. In particular, as the men underwent the prostate cancer treatment it was more often, they who did more talking regarding their experience of the prostate cancer treatment.

### 4.7.3.4. Individual interviews

During the data collection process two of the interviews were individual interviews with men only. Although the primary aim of this study was to capture couples' experiences of prostate cancer treatment, the partners of these men did not attend the interview when I visited. Both interviews were scheduled at the respective homes of the participants and prior to the interview I had contacted the men and we agreed that I would interview them with their partners. However, when I attended, only the men were present. Although I suggested re-scheduling the interview when their partner would be available, the men wanted to conduct the interviews on their own but explained that another interview could be scheduled when their partner could be present. As these were individual interviews with the men alone, careful consideration was subsequently given as to how best to proceed. The decision I made at the time was to conduct the interviews, it seemed the most pragmatic, real-time option. Although it was agreed to re-schedule another interview when their partner would be available, this never materialised although I contacted both men on two separate



## Methodology

occasions (one and two weeks after the original interview) to re-schedule the interview.

However, having conducted both interviews on different days, I then had to consider whether to include the data in the research itself. As the partner was not physically present during the interview, it could have resulted in a less rich account as, for example, the couple could not discuss what the other articulated during the interviews. However, as the study focused on the experiences and impact of prostate cancer treatment, after some deliberation, it was felt that, on balance, the views and perspective of these men could provide additional information on their experiences and perceptions of the healthcare system. In addition, as these men formed part of the marital dyad, their views and experiences can still be considered to be relevant to this study.

Although the primary aim of this study was to investigate the shared experience from a couple's perspective, specific attention was also given to differences in male and female experiences by giving the couples the option to participate in individual interviews following the dyadic interview schedule. It has also been argued that interviews which investigate the dyad as a unit but adopt individual interviews, that a partner can be considered to be virtually present in the interview space (Eisikovits and Koren 2010). As the experiences of these men were similar to the other men in the study, and similar topic areas were covered within the interviews, the individual interviews were included in the data collection and analysis process. Although no new topics or categories were identified from a couple's perspective, these interviews provided additional information about some of the issues faced specifically by the men whilst dealing with the consequences of prostate cancer treatment. However, as discussed earlier, it is acknowledged that it was not possible to achieve the same dynamics from the individual male only interviews.

### 4.7.4. Managing the interviews

Qualitative interviewing involves entering the life-world of participants (Opdenakker 2006), therefore one of the most important elements of in-depth interviewing on a sensitive topic is the ability for the researcher to develop a rapport with participants (Karnieli-Miller et al. 2009). To develop a rapport with participants several strategies were adopted, such as the use of self-disclosure, and participants were asked to choose a place where they could most comfortably participate in the interview.

#### 4.7.4.1. Self-disclosure prior to interviews

Self-disclosure is the process of revealing appropriate information about one's self to the participants (Peters et al. 2008). This is commonly advocated in feminist research for a greater engagement with participants. For this study, prior to the start of each interview, I revealed my personal connection to the study and its participants as a therapeutic radiographer previously employed within the oncology hospital where I would have treated men with prostate cancer and interacted with their partners. I also revealed my current role as a lecturer and educator in undergraduate radiography. As the study involved married couples in Malta, I revealed to the participants that I had been living in Malta for the last 10 years and married a Maltese woman in 2016. The purpose of this self-disclosure was to enhance the reciprocal nature of the interview through an established rapport with the participants (Abell et al. 2006).

#### 4.7.4.2. Interview setting

Participants were asked to choose a time and place where they felt most comfortable. This included home interviews or, in a private room at the local hospital. A total of 14 (12 couples and two individuals) interviews were conducted, four interviews were undertaken at the

## Methodology

hospital and 10 interviews at the participants' homes. All interviews were audio recorded and lasted between 30-80 minutes.

When interviews took place in the hospital, I ensured that a suitable environment was booked in advance. Several potential rooms were identified by the manager of the oncology hospital, I decided to conduct the interviews in the library room as this was close to the main reception and relatively quiet as it was not directly in the radiotherapy department and was therefore a more neutral ground. To ensure that participants were comfortable drinks and light snacks were provided.

As interviews were being recorded, specific attention was given to explaining to the participants that the data would be kept strictly confidential and stored securely, in accordance with relevant REC approvals and data protection legislation. All the interviews were recorded using a digital voice recorder (Sony, ICD PX312). The use of a recorder allowed me to focus on the interview and listen to the participants instead of taking field notes. In addition, the use of a recorder allowed the creation of verbatim interview transcripts which provided an accurate account of the interview in more detail when compared with taking field notes (Opdenakker 2006).

### 4.7.5. Pilot interviews

When conducting a qualitative inquiry, researchers can pilot the interview schedule to assess the acceptability of the interview process (Holloway 1997).

Piloting an interview schedule provides the researcher with an opportunity to assess the appropriateness of the schedule itself and its ability to provide relevant data to answer the research question(s). It can help identify potential limitations of the interview schedule that would subsequently allow necessary modifications to be made, prior to the main study (Kvale, 2007). Piloting can also be used to self-evaluate one's readiness, capability, and commitment as a qualitative

## Methodology

researcher (Lancaster et al. 2004; Beebe 2007). In this sense, pilot work can be used to develop qualitative interviewing techniques (Kilanowski, 2006) and to enhance the credibility of a qualitative study (Padgett, 2008).

For this current study, the piloting of the interview schedule was conducted with the first two couples recruited to this study and transcripts of each interview were forwarded to the supervisors for their feedback. Although an interview guide was prepared, I learned that it was almost impossible to determine how participants were going to answer the questions. There were times where the couple discussed topics which were meant for subsequent questions, or they added to points mentioned earlier in the conversation.

Based on the feedback received from the supervisors it was recommended that more probing and follow-up questions were included in the interview and suggestions were added to the transcripts. I therefore included more probing, follow up questions, where appropriate, in subsequent interviews such as 'can you tell me more about that?' or 'you said.....can you tell me more about what you mean by that?' Verbal probing can also encourage people to continue talking so that more details are provided and a better understanding of the topic is gained (Kallio et al. 2016). Examples of verbal probes that were included in subsequent interviews included: repeating the participant's words, summarising main ideas or expressing interest with verbal agreement (Whiting 2008).

According to Harding (2013), piloting of qualitative interviews is less obvious as he suggested that as interviews progress, the quality of the interview guide improved. However, I found that piloting the interview schedule, and subsequent feedback from supervisors, proved invaluable in the development of my interviewing skills. As the interview schedule allowed the topics to be investigated appropriately, no major changes were made to the interview schedule. However, as

## Methodology

it was difficult to determine the direction of the interview and order of topics to be covered, the interview schedule was slightly modified to include a list of general topics to be covered during the interview but with no specific order, this allowed greater flexibility according to the responses of the participants.

As no significant changes were made to the original interview schedule, besides the option to include individual interviews following the dyadic interviews, data from the two pilot interviews were included in the main study.

### **4.8. METHODS OF DATA ANALYSIS**

In this study, the Braun and Clarke (2006) method of thematic framework was used to guide data analysis. Data analysis involved an inductive approach and was firmly based on the data itself, rather than being influenced by pre-existing theories. An interpretive level was adopted to not only investigate the explicit meaning of the data but to further examine the underlying ideas and assumptions within the data. To assist the process of data analysis, a computer assisted qualitative data analysis software programme (QSR International's NVivo 12) was used and the approach to data analysis is further discussed in this section.

#### **4.8.1. Inductive or deductive approach**

Themes or patterns can be identified within the data using an inductive approach or in a theoretical or deductive approach. An inductive approach means that themes and codes that are identified by the researcher during the analysis process have a strong relationship with the original data (Azungah 2018). In this approach the researcher does not try to fit a specific pre-existing coding framework to the data: instead, codes and themes are generated from the data itself. In contrast to this approach, a theoretical or deductive approach tends to be driven by a pre-determined theoretical or coding framework and/or

## Methodology

analytical interest of the researcher and is thus more analyst driven. For this study I did not use a pre-determined theory at the start of the data collection and/or analysis, therefore an inductive approach to data analysis was undertaken.

### 4.8.2. Explicit / interpretive level

Themes driven from codes can be identified at a semantic/explicit level or at latent/interpretive level (Boyatzis 1998). In an explicit approach, themes are identified within the explicit meaning of the data and the researcher does not seek for anything beyond that which a participant has explained. A thematic analysis at an interpretive level goes beyond the explicit content of the data, it starts to identify or examine the underlying ideas, assumptions and conceptualisation which inform the semantic content of the data. For this study a latent or interpretive level was used to not only investigate the explicit meaning of the data but to further examine the underlying ideas and assumptions within the data. Such an approach involves interpretation by the researcher and therefore the analysis produced is not just a description but includes broader assumptions, structures and/or meanings which are theorised as underpinning what is actually articulated in the data.

### 4.8.3. Thematic Analysis

A thematic analysis approach was adopted to analyse the data. Thematic analysis is a method of identifying, analysing, and reporting patterns (themes) within data. It organises and describes a data set in detail and can be used to interpret various aspects of the research (Boyatzis 1998). Thematic analysis is one of the most popular approaches for making sense of qualitative data (Boyatzis 1998). One of the strengths in this approach is that it is flexible and does not prescribe a particular method of data collection or methodology (Braun and Clarke 2006). According to Braun and Clarke (2006) thematic analysis is a useful method for examining perspectives and differences

## Methodology

between participants and can be used to identify new unanticipated insights. It is also useful for summarising key features of a large data set as it compels the researcher to take a well-structured approach to handling data and helps them to produce a clear and organized final report (King 2004). Such an approach was used to provide a detailed description of the experiences of couples undergoing prostate cancer treatment. As this study primarily collected data from couples, the flexibility of the chosen approach allowed me to capture the broad understanding of this phenomenon of interest. Braun and Clarke (2006) argue that the use of thematic analysis should be considered as a foundational method for qualitative data analysis. A rigorous thematic analysis can produce trustworthy and insightful findings (Braun and Clarke 2006).

To perform the data analysis the strategy adopted followed the guidelines by Braun and Clarke (2006). Namely, a six-phase process that includes the familiarisation, generation of initial codes, searching for themes, reviewing themes, defining and naming of themes and producing a final report. Although the data analysis will be outlined according to these phases, the process was not linear and movement back and forth between the data was frequently needed during data analysis.

### 4.8.3.1. Familiarisation phase

Data analysis started with a process of familiarisation or an 'immersion' in the data. The aim of this phase was to become familiar with the data set and to develop initial thoughts and ideas that may be relevant to the research and or research question. For this study, I immersed myself in the data by listening to each of the audio recorded interviews again to become familiar with the data during the transcription process. I also decided to transcribe all the interviews verbatim myself to further facilitate familiarity with the data. Bird (2005) argues that transcribing the interviews should be seen as an integral

## Methodology

part of the interpretive qualitative methodology. Furthermore, the close attention needed to transcribe data may facilitate the close reading and interpretative skills needed to analyse the data (Lapadat and Lindsay 1999). During the transcribing, initial thoughts and ideas for initial codes and even tentative sub-themes/themes were included in the researcher diary (Appendix four).

### 4.8.3.2. Generation of initial codes

Codes identify a feature of the data that appears interesting to the analyst, and refer to “the most basic segment, or element, of the raw data or information that can be assessed in a meaningful way regarding the phenomenon” (Boyatzis, 1998 p63). Charmaz (2001) describes coding as the ‘critical link’ between data collection and the explanation of meaning. A code is a researcher generated construct that symbolises and thus attributes interpreted meaning to data. Codes are often used to retrieve and categorise similar data chunks so that the researcher can identify, pull out, or cluster the segments relating to a particular research question, construct or theme (Miles et al. 2014).

Data were analysed line by line and codes were first assigned to data chunks to detect recurring patterns. From these patterns, similar codes can be clustered together to create a smaller number of categories. The interrelationships between the categories can be used to develop higher level analytical meaning (Miles et al. 2014). To create the codes, a mix of data derived, and researcher derived codes were created for each data set. Data derived codes are based on the language and meaning of the participants and these do not necessarily need to be interpreted by the researcher as such (Miles et al. 2014). Such codes may constitute pertinent words or phrases directly used by the participants.



## Methodology

In addition, researcher derived codes were created which went beyond the explicit meaning of the participants and required a deeper level of engagement with the data. NVivo software was used in this regard as it offered a straightforward way to read through each interview transcript, whilst directly selecting and assigning particular words or phrases into new or existing codes. More codes were developed as I read through all the interview transcripts, this at times meant returning to transcripts that I had already coded to evaluate whether there were any relevant phrases or data that could also be categorised into the newly developed codes.

Braun and Clarke (2012) argue that it is impossible to be purely inductive, as the researcher always brings something to the data when analysing it. The researcher needs to consider the content of the data to decide whether it is worth coding the data for a particular construct and not another. In this context, and upon reflection, most of the initial codes I developed and used were descriptive in nature since my main focus at that point was to describe the data. However, as I progressed through this phase and read through more transcripts I was also increasingly applying 'interpretive' codes to the data, which in contrast to descriptive codes, were derived from my interpretation of particular words or phrases mentioned by the participants. For example, when I interpreted that a long waiting time and delays had a negative impact on the emotional state of the couple, I later initially coded such an excerpt with 'Long waiting time negatively impacts the emotional functioning of couples'.

Throughout this phase I was also attentive to record notes in my reflective diary of any phrases or excerpts deemed noteworthy, controversial, or unusual. For example, differences in the adjustment to the changes caused by prostate cancer between the men and their wives were noted and therefore coded. Furthermore, my initial thoughts about the main points being mentioned in each interview

## Methodology

were also recorded in my reflective diary. This was done so as to document aspects that may have influenced my reflexivity during the data analysis (Appendix four).

### 4.8.3.3. Searching for themes phase

The searching for themes phase involved the sorting of the different codes into broader levels of themes. The different codes were initially combined into relevant sub-themes and emerging themes and discussed critically with my supervisors and recorded in the researcher diary to ensure transparency. In particular, overlap or similarities between the initial codes were noted and codes were grouped and combined into larger sub-themes and/or themes (Table 3).

## Methodology

Table 3: An example of the development of code into candidate theme

<b>Question</b>		
How would you describe your experience leading to the initial prostate cancer diagnosis?		
<b>Quote</b>	<b>Code</b>	<b>Candidate theme</b>
<p><i>'I had problems with my urination and I went to Mr X and he told me that my prostate is enlarged but then he told me that we were checking the PSA frequently and it was more or less on the 6 side but it was stable and he told me as long as it is stable there is nothing to worry about.'</i></p> <p>(M03)</p>	<ul style="list-style-type: none"> <li>- Help seeking</li> <li>- Enlarged prostate</li> <li>- Stable PSA reading reassuring</li> </ul>	Initial impact of prostate cancer

This phase involved careful analysis and review of the coded data to identify instances where there were similar or overlapping codes. For these instances, I investigated how to develop new categories or subthemes which could be used to incorporate or cluster similar or overlapping codes together, according to the meaning or feature that they shared. Such a process required numerous cycles, whereby it was sometimes also necessary to reword the categories and/or subthemes to allow them to be more inclusive and representative of the codes clustered within them, as well as to truly reflect a logical and meaningful pattern in the data (Braun and Clarke, 2006).

## Methodology

Initially the dyadic analysis procedure is similar to that performed in qualitative studies at the individual level: highlighting significant statements, sentences, and quotes that provide an understanding of how the participants experienced the phenomenon. Unique to dyadic analysis is the examination of the themes emerging from the couple's individual narratives. This is performed by assessing contrasts and overlaps between the different accounts of the men and their spouses (Eisikovits and Koren 2010).

The use of computer assisted qualitative data analysis software, which will be further explained in Section 4.8.4, was used to identify overlap and contrast between the individual accounts. In particular the matrix coding query allowed the automatic searching for codes and themes that were specific for each member of the couple dyad or were shared. Below are two examples (Figure 3 and Figure 4) of the matrix coding queries that were run in order to identify codes that were specific for either male or female participants.

Figure 3 :Matrix coding query for codes specific to males

The screenshot shows the Matrix Criteria software interface. The search criteria are set to "Files & Externals" with "Coding at rows" set to "And" and "columns" set to "Hierarchical Name". The rows are defined by the criteria: "Codes\\thematic framework\\WAITING TIMES OR TREATMENT DELAY" and "Codes\\thematic framework\\WAITING TIMES OR TREATMENT DELAY\\AVOID WAITING TIM". The columns are defined by the criteria: "COUPLE INTERVIEWS:Gender = Male". The results table shows the following data:

Code	Count
1 : Negative emotional impact	81
2 : Keep normal or busy routine	33
3 : SEXUAL IMPACT AND CONSEQUENCES	31
4 : WAITING TIMES OR TREATMENT DELAY	27
5 : Positive treatment experience	24
6 : negative treatment experience	23
7 : TREATMENT DECISION	22
8 : Dealing with it on your own or KEEP UNDER CONTROL	21
9 : urine side effects	21
10 : Compare to others	20

## Methodology

Figure 4 :Matrix coding query for codes specific to females

The screenshot shows the 'Matrix Coding Query - Results Preview' window. The search criteria are 'Files & Externals' and 'Selected Items...'. The rows are 'Codes\thematic framework\WAITING TIMES OR TREATMENT DELAY' and 'Codes\thematic framework\WAITING TIMES OR TREATMENT DELAY\AVOID WAITING TIM'. The column is 'COUPLE INTERVIEWS:Gender = Female'. The table below shows the results for 10 codes.

Code	Count
1 : Negative emotional impact	45
2 : NEGATIVE IMPACT	24
3 : Keep normal or busy routine	19
4 : SUPPORT HUSBAND	19
5 : from partner	16
6 : NOT INVOLVED	12
7 : to get feedback from partner regarding health	11
8 : lack of support or unsupportive	11
9 : Marriage strength	10
10 : Negative Perception	8

In addition, the matrix coding query was also used to identify overlap and contrast between the male and female participants as can be observed in Figure 5 below:

Figure 5 :Matrix coding query for male and female

The screenshot shows the 'Matrix Coding Query - Results Preview' window. The search criteria are 'Files & Externals' and 'Selected Items...'. The rows are 'Codes\Second framework\REFRAMING THE RELATIONSHIP\LIFESTYLE CHANGES\positive c' and 'Codes\Second framework\REFRAMING THE RELATIONSHIP\Marriage strength'. The columns are 'COUPLE INTERVIEWS:Gender = Male' and 'COUPLE INTERVIEWS:Gender = Female'. The table below shows the results for 10 codes.

Code	Male Count	Female Count
1 : Negative emotional impact	80	45
2 : MAINTAINING NORMAL ROUTINE	33	19
3 : SEXUAL IMPACT	31	4
4 : negative treatment experience	25	3
5 : Positive treatment experience	24	3
6 : TREATMENT DECISION	22	1
7 : Dealing with it on your own or KEEP UNDER CONT...	21	1
8 : urine side effects	21	8
9 : To Others	20	5
10 : Support or information needs	19	16

## Methodology

Overlap of codes was identified for several of the initial themes such as the negative emotional impact of prostate cancer, for example distress or anxiety, maintaining normal routine and support or information needs. On the other hand, initial themes such as the sexual impact of prostate cancer, treatment experience and making a treatment decision were more commonly associated with individual participant accounts. This process led to the development of themes that were either 'shared 'or common between the couple(s) as well as themes that were specific for male or female participants.

### 4.8.3.4. Reviewing themes phase

The next phase involved reviewing of the initial themes. This started with reviewing at the level of the coded abstract. It involved reading and reviewing all the coded extracts in each theme in order to consider whether the different codes formed a coherent pattern. According to Patton (1990) codes should be evaluated or judged according to their internal and external homogeneity. This means that the items and codes are appropriate to inform the theme (internal homogeneity). During this process some of the themes needed to be re-named to capture the essence of the individual codes and certain codes were moved from one theme to another as they did not fit the theme. Once all themes were evaluated and judged according to their internal homogeneity, the next step involved assessment according to their external homogeneity. External homogeneity is assessed in order to determine whether a theme is appropriate to inform the interpretation of the data set. This involved consideration of the theme accurately reflecting the meaning which was evident in the interviews.

### 4.8.3.5. Defining and naming themes phase

Following review of the themes the different themes needed to be defined and named. This involved capturing the essence of each theme (Braun and Clarke 2006). For each theme or construct, a detailed report or analysis was created to capture the meaning of the

## Methodology

theme in accordance with the data. This process involved the defining and naming of the overarching themes as well as potential subthemes.

### 4.8.3.6. Producing a report phase

The final phase was the production of a report, this is presented in the findings chapter. Sufficient evidence of the themes in the data, with the assistance of data extract, was included to demonstrate the prevalence of each theme. A detailed process of the data analysis process can be found in Appendix five.

As large amounts of textual data, in the form of transcripts and field notes, needed to be analysed a Computer Assisted Qualitative Data Analysis Software (CAQDAS) was used and will be discussed in more detail in the following section.

### 4.8.4. Computer assisted qualitative data analysis software

Analysing qualitative data is a critical component of qualitative research (Miles et al. 2014) and involves the process of coding, verifying, and exploring the research data (Saldaña, 2009). However, the process of qualitative data analysis has been described as extremely time-consuming and sometimes mysterious (Alvesson and Karreman 2011). The use of a Computer Assisted Qualitative Data Analysis Software (CAQDAS) allowed me to look at patterns of codes and links between codes across large fields of data. According to Creswell (2012) the use of CAQDAS offers the researcher the ability to rapidly identify text labelled with a given code across transcripts or the ability to store and analyse visually amongst other capabilities (Creswell 2012).

A CAQDAS programme can lessen the burden of the systematic and rigorous preparation and analysis of qualitative data. The use of CAQDAS allowed me to engage in analytical practices extending

## Methodology

beyond the limits of manual/paper-based techniques, most notably to support coding and retrieval of data, differentiate coded data by participant characteristics, and investigate conceptual relationships. In addition to this, CAQDAS can be used to make the analytical process more transparent by using programme outputs to illustrate the coding process and researcher outputs (O’Kane et al. 2019).

To aid me in data analysis, QSR International’s NVivo 12 qualitative data analysis software was therefore used. The strength of NVivo lies in its high compatibility to research designs. The software is not methodologically specific and therefore can be used for a wide range of qualitative research designs and data analysis methods. This software tool assisted me in the analysis process, particularly in relation to looking at patterns of codes and links between codes across large fields of data. A detailed description of the data analysis process can be found in Appendix five.

### **4.9. ETHICAL AND GOVERNANCE CONSIDERATIONS**

The term ethics is derived from ethos, referring to the values and customs of a culture at a particular point in time (Polgar and Thomas 2013). Ethics are systems of moral principles that guide human action and in 1964 the Declaration of Helsinki by the World Medical Association was a seminal global event in the development of research ethics principles and processes (World Medical Association 2013). The declaration was an elaboration and development of the 1947 Nuremberg Code which was a response from the judges at the Nuremberg war crime trial for the cruel and harmful research carried out during the Second World War.

There have been numerous codes of medical ethics published in various countries and professional bodies that have been guided by the Helsinki declaration. Although these codes somewhat vary between countries, they often have the same foundation. For this



## Methodology

study, ethical approval was first sought and obtained by the host higher education institution (School of Healthcare Sciences, Cardiff University), this was followed by obtaining ethical clearance from the local institution (Faculty of Health sciences, University of Malta) to be able to collect data (Appendix two).

The main ethical principles discussed in this section include respect for autonomy and informed consent, anonymity, and confidentiality and minimising risk and harm to participants.

### 4.9.1. Respect for autonomy and informed consent

One of the main ethical principles that should inform healthcare research is respect for the autonomy of the people being studied (Hammersley and Traianou 2014). Autonomy refers to the notion that individuals are allowed to make a free choice regarding participation and that one should respect an individual's right to choose, regardless of the decision made. The voluntary expression of consent by an individual taking part in research, and the adequate information disclosure about the research, are critical and essential elements of the informed consent process (Nardini 2014). These principles are often made explicit when gaining informed consent and details of the processes adopted in this study are outlined in the informed consent section below.

#### 4.9.1.1. Informed consent

In accordance with REC approval, participants were identified, approached, and recruited into the study by clinical gatekeepers as outlined in Section 4.7.2.2. Participants were contacted by myself to agree on a suitable location and time for the interview and to answer any additional questions that they had. Prior to each interview I ensured that both participants had read and understood the participant information sheet that had been sent to them previously and I answered any additional questions. When they were ready to consent

## Methodology

to be interviewed for the research, and I was satisfied that they had been fully informed, a consent form (Appendix three) was signed and dated by myself and the interviewees. Participants were also informed that they could pause or stop the interview at any time, choose not to answer any question and/or withdraw from the study, without prejudice, if they so wished.

### 4.9.2. Anonymity and Confidentiality

Given that qualitative studies often contain rich descriptions of study participants, the dissemination of such information may lead to the identification of study participants. Confidentiality breaches via deductive disclosure are of particular concern to qualitative researchers. Deductive disclosure can occur when details of an individual or a group make them identifiable in research reports (Sieber 1992). As such, qualitative researchers face a conflict between providing sufficient detail, whilst also protecting participants' identities.

The most common approach to protecting study participants from identification is assigning pseudonyms or identification (ID) codes. However, the use of pseudonyms alone may not be sufficient to protect against identification of participants. For example, Ellis (1995) presents an account of the harm caused to her participants in a study of a small fishing community. The pseudonyms used to secure both internal and external confidentiality had failed to sufficiently obscure their identity, as a result relationships in the community were subsequently strained because of the information contained in Ellis' research. Members of the community felt betrayed and humiliated by the research (Ellis 1995). Such a breach in confidentiality can also damage the public's trust in research (Allen 1997). The work of Ellis (1995) was conducted in a small community whereby it may have been easier to identify individuals based on a detailed description.

## Methodology

Similarly, this current study took place in what can be considered as a small community. The total population of the Maltese islands is relatively small, with an estimated population of 516,100 at the end of 2020 (National Statistics Office [Malta] 2021). In such a relatively small population, compared with many European countries, it could make it easier to identify individuals. As this study included couples who underwent prostate cancer treatment, the population is even further restricted and therefore could result in the identification of participants. Although this small population has often been discussed in relation to traditional ethnographic studies which focus on particular villages or towns (Van den Hoonaard 2003; Walford 2005), it could be seen as a concern for participants in this study.

Several methods were therefore adopted to minimise the risk of breaching confidentiality, this included changing names, places, occupation, and moderating other potentially identifiable data. These will be discussed in more detail in the subsections below.

### 4.9.2.1. Names

Personal names which could make it possible to identify an individual were removed/altered. Participants were not given a pseudonym, but as suggested by Corden and Sainsbury (2006) were given an ID code based on characteristics such as gender and a specific number according to the chronological sequence of interviews. In addition, the names of other relevant individuals, for example participants' doctors and GPs were also removed as the naming of these individuals might also reveal their identity.

### 4.9.2.2. Places

The assignment of places followed a similar pattern, any references to an area or town were removed from the transcripts and reports. Other names or places, such as the hospital or private clinics they attended, were also removed and simply referred to as 'general hospital' or

## Methodology

'private clinic'. It has been suggested that such anonymisation of places can result in decontextualization, limiting the scope for analysis (Baez 2002). It was however ensured that the context of these settings was not entirely decontextualized, for example a reference to an individual having undergone medical treatment in a specific country was replaced with 'medical treatment in an overseas EU country'.

### 4.9.2.3. Other potential identifiable issues

Over and above names or places there are often features which could be seen as unique (or closely narrowing) and therefore may result in the participant being identifiable. For example, occupation can also be seen as relevant for the data analysis and therefore difficult to simply remove or alter. However, it could also be used to identify an individual, therefore the occupation or previous occupation of the participants was substituted with general terms. In addition, during the data collection and analysis it was noted that certain features, such as being involved in an accident at work, could be used to identify the individual. Other examples included suffering from a particular medical condition from a young age. These unique aspects in the data were replaced with more general descriptions in order to maintain their anonymity.

### 4.9.3. Confidentiality

Confidentiality in research refers to agreement with participants about what may be done with the data that arises from their participation (Sieber 1992). To ensure confidentiality throughout the study all records were stored securely, in accordance with General Data Protection Regulation UK (Data Protection Act [UK] 2018) and the EU General Data Protection Regulation (GDPR) (European Commission 2016). Confidentiality is underpinned by the principle of respect for autonomy, it refers to the notion that identifiable information about individuals which has been collected during the process of research will not be disclosed without permission (Wiles et al. 2008). As outlined

## Methodology

previously, identifiable information from participants was removed or altered to protect the identity of participants. In addition, the data gathered during this study was only shared with the primary supervisors, permission was obtained from all participants to use anonymised quotes in reports and publications related to this research.

For this study, confidentiality was fully explained both in the information sheet and consent form and prior to each interview. Participants chose the location for the interviews, somewhere they would feel comfortable whilst taking into account the need for privacy and confidentiality (Griffith and Tegnah 2013).

### 4.9.4. Minimising risk and harm to participants

Qualitative interviews have the potential to evoke emotions for participants both during and after the interview (McLeod 2003). Participants may find themselves affected by research questions that touch on unresolved conflicts or other emotional issues that they have not anticipated and were not prepared to discuss (Grafanaki 1996). In addition, Smythe and Murray (2000) discussed one pervasive risk factor in qualitative research in terms of "the subtle and often unforeseeable consequences of writing about people's lives" (Smythe and Murray 2000p. 321) and, in particular, "the emotional impact of having one's story reinterpreted and filtered through the lenses of social scientific categories" (Smythe and Murray 2000p. 321).

As this study investigated the experience of couples undergoing prostate cancer treatment, during the ethical approval of this study it was identified that participants may find it upsetting to discuss some of their experiences. Although the potential risk for participants was considered to be low, appropriate support mechanisms were made available for these couples, such as providing the contact details for the clinical psychologist at the oncology hospital, should further support be required. In addition to this, the interviews were managed

## Methodology

in a considered and sensitive manner and were followed by a debriefing session. Kvale (1996) suggests that the interviewees be provided with a context for the interview before and a debriefing afterwards. The debriefing took place after the audio recording device had been turned off, it allowed the participants to think about the interview process and ask any related questions. None of the participants appeared to be upset following the interview and I provided the participants with my contact details and information regarding available support services, should additional support be required. Furthermore, none of the participants contacted me after the interviews.

### **4.10. TRUSTWORTHINESS**

When assessing the quality or rigour of a study the concepts of validity and reliability, as commonly used in the positivist paradigm, cannot be addressed in the same way. Unlike quantitative researchers who apply a variety of techniques or statistical tests to establish validity and reliability of the research, in qualitative research methodological strategies are adopted to ensure rigour, 'soundness' or trustworthiness of the study.

Although there is no universally accepted terminology and criteria to evaluate rigour of qualitative research, the use of multiple procedures has been recommended to enhance the accuracy of findings as well as convince readers of the accuracy. Some authors such as Lincoln and Guba (1985) offer alternative criteria for demonstrating 'trustworthiness' of qualitative research. Lincoln and Guba (1985) suggest that the trustworthiness of this study can be explained in terms of credibility, transferability, dependability, and conformability and these are further presented below.

## Methodology

### 4.10.1. Credibility

Lincoln and Guba (1985) argued that ensuring credibility is one of the most important factors in establishing trustworthiness. Credibility represents the issue of 'fit between the respondent's views and the researcher's representation of them (Tobin and Begley 2004). Credibility can be established through a detailed description of all phases of the research process, including but not limited to the research design and setting, the study sample and recruitment process, and the methods used to collect data (Denzin and Lincoln, 2017). In addition to a detailed description, prolonged engagement of the researcher in the field, together with triangulation of investigators can all further contribute to the credibility of a research study. My previous experience as an employed therapeutic radiographer, and still having a close connection due to my role as an educator for the undergraduate course in radiography, allowed me to have a thorough understanding of the prostate cancer treatment process. Furthermore, having lived in Malta since 2009, and being married to a Maltese woman, provided me with a thorough understanding of the local and cultural setting as well as the health setting in which this study took place. My personal and professional experiences can be considered to enhance my researcher credibility (Patton 1990) and this is further presented in Section 4.11.1.

In addition, investigator triangulation was used during key stages of the data analysis process and involved using more than one observer, coder, or data analyst in the study. Such an approach can be used as a confirmation of data amongst investigators and lends greater credibility to the observation (Denzin and Lincoln 2005). For my study, the raw data of the interview transcripts were shared with the supervisory team, and these were independently coded. Following this exercise, a meeting was scheduled to compare the coding schemes, differences and deviations between the codes were discussed. This process informed my interpretation of the data and allowed for the

## Methodology

further refinement of codes. It should be acknowledged that thematic analysis is considered to be a reflection of the researcher's interpretive analysis of the data conducted at the intersection of the data set, the theoretical assumptions of the analysis and the analytical skills/resources of the researcher (Braun and Clarke 2019). Therefore, it is appreciated and even expected that different researchers will interpret the data differently. However, the use of multiple coders can be particularly beneficial in a reflexive manner to sense-check ideas and to explore multiple assumptions in the interpretation of the data (Braun and Clarke 2019). The use of the additional investigator in my study was particularly beneficial for collaboration and reflection on the assigned codes, aiming to achieve a richer interpretation of meaning rather than achieving consensus of meaning.

The same process was adopted when themes were developed from the initial codes. To ensure transparency of the entire process, discussions and disagreements were recorded in the researcher diary. In addition to this, regular meetings with supervisors were undertaken throughout the research journey, this ensured ongoing critical reflection of methods to ensure sufficient depth and relevance of the study (Sandelowski 1993). Furthermore, the use of original quotes in the write up enabled the reader to determine the truthfulness of the researchers' interpretation of such data.

### 4.10.2. Transferability

Transferability concerns the aspect of applicability of the research findings in other settings (Lincoln and Guba, 1985). Lincoln and Guba (1985) recommend providing a 'thick' description of the phenomenon under investigation. A "thick" description of the participants, research process and their context enable the reader to assess whether the findings are transferable to other settings. Whilst it is acknowledged that it is still difficult to make claims about transferability of the findings arising from this study to other populations or settings, attention has



## Methodology

been given to providing a 'thick' and detailed description of the entire research process. This is necessary to help the reader decide whether the reported findings, concepts and/or inferences can possibly be transferable or applicable to other similar settings. In fact, this study was carried out in a single site oncology hospital in Malta which serves all local oncology patients. A description of the context in which the study was carried out, its setting, sample size and socio-economical and clinical characteristics have also been provided (See Section 2.7). In addition, comprehensive details of the methods employed have been documented. Collectively such information should help the reader establish whether findings from this study could be transferred to other settings.

### 4.10.3. Confirmability

Confirmability concerns the aspect of neutrality (Lincoln and Guba 1985). The researcher needs to ensure the inter-objectivity of the data. This means that the interpretation should not be based on the researcher's own particular preferences and viewpoints but is grounded in the data, although it is acknowledged that analysis of data inevitably involves interpretation of the data by the researcher. Steps must be taken to help ensure, as far as possible, that the work's findings are the result of the experiences and ideas of the participants, rather than the characteristics and preferences of the researcher. To ensure that the interpretation and findings are the result and ideas of the participants, peer debriefing was adopted. This process enhances the accuracy of findings, it involves locating a person who reviews and asks questions about the qualitative study so that the account resonates with other people besides the researcher (Henry 2015). This strategy involves interpretation by another person and therefore adds rigour. Peer debriefing was adopted at key stages of the data analysis process, including at the initial stages of coding, as well as subsequently during the development of themes.

## Methodology

Peer briefing was adopted throughout this study and included regular debriefing sessions with the supervisory team. The supervisory team consisted of three senior lecturers who are experienced qualitative researchers. According to Sandelowski (1993), the involvement of an experienced qualitative researcher can reduce the potential for lone researcher bias and could provide additional insights into the theme and/or theory development (Sandelowski 1993).

### 4.10.4. Dependability

Dependability includes the aspect of consistency (Lincoln and Guba 1985). Lincoln and Guba highlight the close relationship between credibility and dependability. They indicate that, in practice, a demonstration of credibility will ensure dependability. The strategy needed to ensure dependability is known as an audit trail. Within this study the researcher has provided a complete set of notes on decisions made during the research process, reflective thoughts, research materials adopted, emergence of the findings and information about the data management. This enables the reader to study the transparency of the research path (Appendix four).

## 4.11. REFLEXIVITY STATEMENT

Reflexivity is often termed as the process by which a researcher turns back upon and takes account of themselves (Alvesson et al. 2008). If a researcher clearly describes the contextual intersecting relationships (e.g., ethnicity, socio-economic status, age and cultural background) between the participants and themselves, it not only increases the creditability of the findings (Berger 2015) but can also deepen understanding of the work. Reflexivity has been established as one method which qualitative researchers can use to enhance the rigour and quality of their work (Teh and Lek 2018).

For these reasons, the following section provides the reader with a reflective account of my personal characteristics, beliefs, and views

## Methodology

about the area under study. Subsequently, a discussion of how such factors may have affected my relationships with participants, and/or the eventual analysis, interpretation and presentation of findings, is also provided.

### 4.11.1. Personal and professional characteristics

I am a Dutch male, currently in my mid-30s. Professionally, I am a dual qualified radiographer employed as an assistant lecturer within the Department of Radiography at the University of Malta. In my personal life, I am a husband and a father of two children, both of whom were born during the course of this study. I am married to a Maltese woman and have been living and working in Malta since 2009, I therefore have a thorough understanding of the social and cultural background in which this study took place.

It is also pertinent to add that, prior to this study, my father-in-law was diagnosed with prostate cancer and travelled for brachytherapy treatment to the United Kingdom. This experience, as a close family member, also provided me with an additional personal insight into the potential impact, concerns and expectations associated with undergoing prostate cancer treatment.

### 4.11.2. Insider/outside research

As a radiographer, living and working in Malta I can perhaps be considered as a relative 'insider' to the research area and phenomenon being investigated. Insider research has been described as a study in which the researcher is also 'a member' (Brannick and Coghlan 2007) of that particular community. Whilst recognising that insider research is critiqued as it could lead to potential researcher bias, it has also been argued that an insider to the research area can be advantageous as it allows the researcher to have insights that 'an outsider' could not have (Bonner and Tolhurst 2002). I felt that my insider status was beneficial as it allowed me to better understand

## Methodology

what was being discussed during the interviews. However, insider research refers to studies where the researcher is also a member of (Kanuha, 2000). As I have not been diagnosed and am not living with prostate cancer, I did not consider myself as an insider, as such. In addition, since I am Dutch the participants could have considered me as a relative outsider with no understanding of the local socio and cultural background. However, as outlined in Section 4.7.4.1, I disclosed my background to the participants prior to the interview in order to establish a rapport with them. Furthermore, such self-disclosure was performed so that participants were made aware that I was familiar with the local socio and cultural environment in which this study took place.

However, as I am in my mid-30s, and participants in this study were men aged between 64-74 years, I did not consider myself as a true insider to the study. I regarded myself as more of an outsider with insider knowledge of the topic area, healthcare system and socio-cultural setting. Such knowledge was considered as valuable for this study as it allowed me to better understand some of the settings and situations that were discussed by the participants, as pointed out by Asselin (2003) dual roles can result in role confusion when the researcher responds to the participants or is analysing the data. According to Asselin (2003) there is a higher risk of bias when a researcher is familiar with the research setting. For this study I consider myself an in-betweenener, which can be considered to transcend the strict binary of insider-outsider positions (Dwyer and Buckle 2009). By adopting the position of an in-betweenener, it could offer a more nuanced understanding of the phenomenon under investigation.

Another aspect that was considered during this study was the use of language, particularly during the data collection, this is discussed in the next section.

## Methodology

### 4.11.3. Language

The current study took place in Malta which is considered to be bilingual, having both English and Maltese as the official languages. A recent adult educational workforce survey revealed that 91% of the respondents stated that Maltese was their mother tongue, with a further 68% of respondents stating that they considered themselves proficient in English (National Statistics Office [Malta] 2018). Although Maltese is considered to be the mother tongue for the majority of Maltese, careful consideration was given whether to conduct the study in English, Maltese or to offer participants a choice of preferred language. Although I have been living in Malta for more than 10 years and have a good understanding of the language in day-to-day conversation, I did not consider myself able to conduct the interviews in Maltese. Therefore, if I wanted to use the Maltese language for interviews or give an option to the participants, I needed to make use of an interpreter during the interviews. Research conducted with people from other cultures may be constrained by such cultural and/or language barriers (Tsai et al. 2004). However interpreters, like researchers, bring their own assumptions and concerns to the research process (Temple and Edwards 2008). According to Tsai et al. (2004), a threat to trustworthiness may exist if the data analysis process does not include those who understand the language and cultures of the participants. One method which has been recommended is to have a member of the group targeted for the study included in the research team (Gil and Bob 1999). Such an approach was also adopted in this study, a local supervisor was included in the study who understood the language and the socio-cultural setting. Furthermore, the use of an interpreter or translator may lead to concerns that the quality of data translation may affect data collection and the accuracy of the study findings (Frederickson et al. 2005).

The sensitive subject matter under investigation was another aspect that I felt important to consider for this study and therefore the impact

## Methodology

of having another person (that is a translator) present during the interview. Researchers often enter peoples' lives at a time of stress and ask them to discuss their experiences (Liamputtong 2022). It is therefore important for a researcher to build an effective research relationship, this is often achieved with rapport-building from the outset (Dickson-Swift et al. 2007). However, I felt that having an interpreter present during data collection could have made it more difficult to establish a rapport and could have hindered the data collection process. I therefore decided to conduct the interviews in English, however I did explain to the participants that they could express themselves in Maltese should they find it difficult to express themselves in English during the conversation. However, only one couple expressed themselves a few times in Maltese when they were unable to voice their feelings in English. These sections were translated, and the original Maltese expressions were also reported.

### **4.12. CONCLUSION**

This chapter considered, in-depth, the methodological approach adopted for this research and the methods employed. A qualitative descriptive approach was considered the most appropriate methodology to meet the aims and objectives of this study, with in-depth interviews undertaken with men who underwent prostate cancer treatment and their partners. Ethical considerations were ensured at all stages of the research process. The next chapter presents the findings from the study.

## **CHAPTER 5. FINDINGS**

### **5.1. INTRODUCTION**

This study explored the experiences of men (aged 64-74 years) and their partners in the first two years following external beam radiotherapy treatment for prostate cancer in Malta. Attention is given to presenting findings from the couples' perspectives while also highlighting, where appropriate, key differences in male and female participants' experiences and perspectives. Findings are presented using relevant data excerpts, where appropriate, from male or female participants to support the findings. The excerpts will help to ensure that the interpretations remain close to the voice of the participants which is congruent with a qualitative descriptive approach. To aid data presentation and better locate the findings, table 4 provides a summary of the participating couples' characteristics. Twelve interviews were conducted as couples where both members of the couple were present, whilst two interviews were with the men alone (interview 7 and 11).

## Findings

Table 4: Participant characteristics of couple interviews

Couple Number	Gender	Age (years)	Employment status	Marital status/ length of marriage	Education level	Time since completing RT (in months)	Interview setting	Management option
01	M	70	Retired	Married (14 years)	Secondary level	7	Home	RT only
	F	57	Clerk		Secondary level	7	Home	
02	M	69	Part-time catering	Married (47 years)	Secondary level	12	Hospital	RT + ADT
	F	69	Housewife		Secondary level	12	Hospital	
03	M	72	Retired	Married (48 years)	Secondary level	16	Hospital	RT + ADT
	F	68	Housewife		Secondary level	16	Hospital	
04	M	70	Retired	Married (12 years)	Secondary level	16	Hospital	RT + ADT
	F	40	Cleaner		Secondary level	16	Hospital	
05	M	71	Retired	Married (49 years)	Tertiary level	24	Home	RT + ADT
	F	73	Housewife		Secondary level	24	Home	
06	M	74	Retired	Married (49 years)	Secondary level	18	Home	RT + ADT
	F	71	Housewife		Secondary level	18	Home	
07*	M	65	Retired	Married (40 years)	Secondary Level	12	Home	RT + ADT
	F	63	Housewife		Secondary level	12	Home	



## Findings

08	M	73	Retired	Married (47 years)	Secondary level	6	Home	RT + ADT
	F	71	Part-time cleaner		Secondary Level	6	Home	
09	M	64	Retired	Married (39 years)	Secondary Level	9	Hospital	RT only
	F	69	Housewife		Primary level	9	Hospital	
10	M	66	Gardener	Married (35 years)	Secondary level	22	Home	RT + ADT
	F	59	Housewife		Secondary level	22	Home	
11*	M	65	Retired	Married (33 years)	Secondary level	14	Home	Post-op RT
	F	59	Housewife		Secondary level	14	Home	
12	M	65	Retired	Married (40 years)	Secondary level	16	Home	Post-op RT
	F	58	Housewife		Secondary level	16	Home	
13	M	64	Retired	Married (40 years)	Primary level	9	Home	Post-op RT
	F	63	Retired		Secondary level	9	Home	
14	M	72	Retired	Married (52 years)	Secondary level	12	Home	RT + ADT
	F	71	Retired		Secondary level	12	Home	
*Men attended alone to the interview								

The couples who attended the interviews were all married and in conventional long-lasting heterosexual relationships and therefore caution should be applied when considering transferability of the findings to other types of partnerships/non-traditional relationships. Although homosexual couples were not excluded from this study, none were recruited into this study.

Transcription of the interview data revealed a series of pertinent, related experiences encountered by the couples as they progressed through the prostate cancer pathway. Thematic analysis of interview

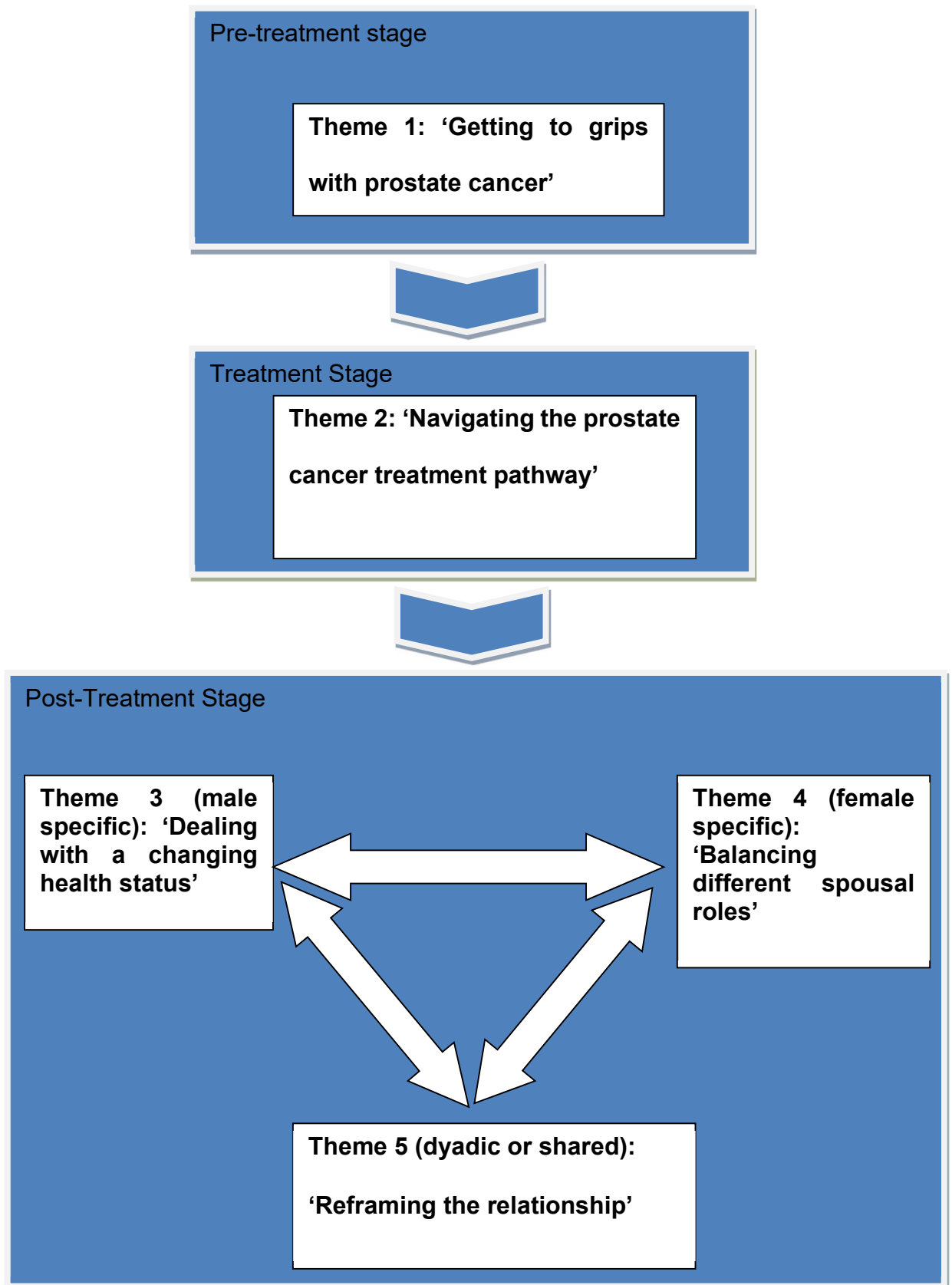
## Findings

data generated five overarching themes, these related to three key phases of the cancer journey. The key phases were pre-treatment stage, treatment stage and post-treatment stage and these are presented in Figure 6.

Although the data provides different participant experiences, there are many similarities between couples' accounts. Sometimes, specific experiences, events or emotions were mentioned by most, but not all. To avoid implying consensus, the term 'most' was therefore used. When experiences, events or emotions were mentioned by a few but not all, the term 'some' was used. To maintain confidentiality, participants are referred to by letter (M=male, F=female) and number (1-14) according to the chronological interview number.

## Findings

Figure 6: Diagram depicting the different themes according to the treatment stage and relationship with each other



## Findings

Theme 1 (Getting to grips with prostate cancer) presents couples' experiences of the pre-treatment phase. This phase included the time period from the discovery of initial symptoms and/or elevated PSA levels until the commencement of treatment. Theme 2 (Going through the prostate cancer journey) presents the experiences of couples from the start of their external beam radiotherapy treatment and includes the initial period after completion of radiotherapy, this is when the men experienced acute side effects of treatment. The last three themes include the post-treatment phase when dealing with the changes caused by prostate cancer and its treatment and dealing with the longer-term impact. Theme 3 (Dealing with changing health status) and Theme 4 (Balancing different spousal roles) include the respective male and female participants' specific individual coping strategies and adjustment to the daily realities of prostate cancer. These themes were separated as findings suggested that the men and their spouses adopted gender-specific strategies whilst dealing with the consequences of prostate cancer. Furthermore, these themes, whilst presented separately, are interconnected as it appears that the strategies adopted by one member of the couple may directly interact with the other. Theme 5 (Reframing the relationship) presents strategies that were shared between the couples, and these were grouped to deal with the emotional impact of the disease.

### **5.2. THEME 1 – GETTING TO GRIPS WITH PROSTATE CANCER**

#### 5.2.1. Introduction

Getting to grips with the prostate cancer theme describes couples' experiences of the early stages of the prostate cancer journey. The elevated PSA levels amongst male participants and subsequent investigations impacted on the emotional wellbeing of couples. Data suggests that they were concerned about the long waiting lists and delays which they experienced prior to diagnosis and commencement

## Findings

of prostate cancer treatment. Couples varied in their willingness to disclose their prostate diagnosis to others, most couples only involved their direct family such as their children. Making a treatment decision was emotionally challenging and couples' preference for involvement in the treatment-decision making process varied. Whereas some participants preferred to be closely involved in decision making, others primarily left the treatment-decision to the specialist. Findings indicated that several men had a change in their initial clinical decision and the provision of information regarding such change was not always perceived as satisfactory.

The getting to grips with prostate cancer theme therefore includes several sub-themes, which are presented in Table 5. This table helps to demonstrate the subthemes, including the corresponding data codes/nodes and data excerpt examples.

*Table 5: Overview of theme 1 – Getting to grips with prostate cancer including subthemes, codes and nodes created from NVivo and excerpt examples*

<b>Theme 1: Getting to grips with prostate cancer</b>		
<b>Subthemes</b>	<b>Codes / nodes</b>	<b>Excerpt example</b>
Initial signs and symptoms / reason for help seeking	<ul style="list-style-type: none"> <li>- Lower urinary tract symptoms</li> <li>- Asymptomatic</li> <li>- Elevated PSA blood levels</li> </ul>	<p><i>'I was getting up around three times during the night to go to the toilet so I went to my GP.'</i></p> <p style="text-align: right;"><i>M02</i></p> <p><i>'So, we did a blood test, and the doctor saw that the PSA was a little bit high 7, and he made another appointment for me at the hospital.'</i></p> <p style="text-align: right;"><i>M10</i></p>

## Findings

<p>Emotional impact</p>	<ul style="list-style-type: none"> <li>- Initial shock</li> <li>- Negative psychological impact</li> <li>- Dealing with uncertainty</li> </ul>	<p><i>'We were shocked, very shocked.'</i></p> <p style="text-align: right;">F01</p> <p><i>'It's how you handle it in your mind because with cancer; it is as much a mental thing as it is a physical thing.'</i></p> <p style="text-align: right;">M14</p> <p><i>'Because it is the unknown if they told it is definitely cancer then you know (sic).'</i></p> <p style="text-align: right;">F03</p>
<p>Disclosing the diagnosis to other</p>	<ul style="list-style-type: none"> <li>- Non-disclosure / close family</li> <li>- Open to all</li> <li>- Reasons for disclosure/non-disclosure</li> </ul>	<p><i>'No, nobody knows about it, just me and the kids, even at work, only two people know about it.'</i></p> <p style="text-align: right;">M02</p> <p><i>'I was telling him do you wake up at night to go to the bathroom and after that, he went to check, and he got diagnosed so that's why it is nice to talk to people.'</i></p> <p style="text-align: right;">M09</p>
<p>Treatment or examination delay</p>	<ul style="list-style-type: none"> <li>- Waiting time</li> <li>- Private hospital appointment</li> </ul>	<p><i>'But I wasn't prepared for all this waiting and waiting and therefore I decided to see Dr X privately and he confirmed there was a problem.'</i></p>

## Findings

	<ul style="list-style-type: none"> <li>- Need to have rapid answers</li> </ul>	<p style="text-align: right;">M14</p> <p><i>'If there is the possibility if someone is suffering from cancer the biopsy should be done immediately! Because, that is maybe my fault because I went privately, but I was worried, and you want to rush things.'</i></p> <p style="text-align: right;">M03</p>
<p>Making a management decision</p>	<ul style="list-style-type: none"> <li>- Decision making in conjunction with close family members</li> <li>- Reason for treatment decision</li> <li>- Information sources</li> </ul>	<p><i>'Well actual discussed this with my doctor and he told me that if I wanted to go for the robotic treatment, most of the people would still go for the radiotherapy treatment too (sic).'</i></p> <p style="text-align: right;">M06</p> <p><i>'I mean it wasn't easy at all and I discussed it with my wife and my son and my daughter I mean everybody had their opinion to do it in Malta or over in England.'</i></p> <p style="text-align: right;">M03</p>

## Findings

### 5.2.2. Initial signs and symptoms

Several of the male participants did not initially notice any prostate-related symptoms and only discovered that they had an elevated PSA after undergoing a blood test for another medical condition. However, some other men initially noticed lower urinary tract symptoms such as nocturia, which led them to seek medical attention:

*'I was getting up around three times during the night to go to the toilet, so I went to my GP.'*

M02

Being informed about an elevated PSA blood level and subsequently being referred to a specialist was emotionally challenging for most men; some described this period as an 'initial shock' and causing 'worry about the future'. Findings suggest that the period from initial referral to a specialist until the actual diagnosis was particularly challenging for them. This period was often associated with uncertainty, and this affected their emotional well-being:

*'I was downcast the first time the GP told me that it could be cancer. It could be! it could be! Listen, it could be cancer! Because it is the unknown if they told it is definitely cancer then you know.'*

M03

The initial elevated PSA levels and the need for further tests and examination also caused a negative emotional impact on the spouse. Spouses often commented on the emotional impact such as worry or fear as a result of a potential cancer diagnosis:

*'That affects you I am sure just the word cancer it puts a fear in you.'*



### 5.2.3. Treatment or examination delays

A common concern for most couples was the long waiting times for additional examination and to start the treatment. Couples indicated that following specialist referral for treatment, they often had to wait more than five months to start treatment. One man commented that his appointment for a prostate biopsy was more than one year following an elevated PSA reading. These long delays increased uncertainty and were of significant concern for most couples:

*'I was seeing Mister X privately. Ok and then finally he said: 'we need to do a biopsy. I would like to do it at hospital but you have to wait for four and a half months'. What? Jesus Christ!?! Another 4 and a half month for a biopsy? and then you have to wait for another 2 weeks for a result. And I said: 'no I will do it privately' and I did it the following day. I mean, it is not about the money, it's not about the money but if there is the possibility that someone is suffering from cancer, the biopsy should be done immediately. Because that is maybe my fault, because I went privately but I was worried and you want to rush things.'*

Following the initial referral, the need for a timely diagnosis appeared to be shared by most couples, this led to most patients making a private hospital appointment with the specialist to expedite the diagnosis and help alleviate the emotional impact, particular the associated uncertainty:

## Findings

*'I wasn't prepared for all this waiting and waiting and waiting and therefore I decided to see Dr X privately and he confirmed there was a problem.'*

M14

The couples often perceived that healthcare professionals did not necessarily treat their case with the level of urgency they felt was appropriate. In particular, participating couples perceived that a potential cancer diagnosis should be treated with urgency and that any delays could result in a worsened outcome:

*'You shouldn't say, because that is the first thing, they tell us: 'listen, don't worry, this takes long, it can take years'. I mean you cannot tell if it is aggressive or not.'*

F13

There appeared to be some disagreement between the couples and healthcare professionals regarding the potential development and growth rate of prostate cancer. Whereas the healthcare professionals often reportedly indicated to participants that prostate cancer tended to be relatively slow-growing, the couples perceived that any delays could have a negative impact on the outcome of their treatment and prognosis:

*'I got frightened, and ok, they mentioned that this is a slow-growing tumour. But I was feeling that this long wait could have a negative impact on the outcome and that the cancer may grow during this period (sic).'*

F13

## Findings

Several couples were also concerned with some of the results they received. In particular, a rapid rise in PSA values or a high-risk prostate cancer diagnosis made them believe that they probably required urgent attention:

*‘They say it is a slow process but I can still not understand why they say that because in December the PSA was Ok but in February it wasn’t anymore and when they did the biopsy it was an aggressive Gleason 8 cancer so WoW. It moves fast it doesn’t move slowly and we were wasting time in my opinion.’*

M03

### 5.2.4. Disclosing the diagnosis to others

After receiving their prostate cancer diagnosis, the couples often considered whether to disclose the cancer diagnosis to others. Findings suggest that wider open disclosure to friends and relatives was not common, and most only informed direct family members (for example children).

The reason for a lack of disclosure to wider family members and friends appeared to vary between couples, most indicated that a cancer diagnosis should, where possible, remain private and only be revealed to their immediate family such as their children. Many appeared concerned that revealing their cancer diagnosis would cause undue concern amongst others, could lead to changes in their perceived relationship with them, beyond the immediate family, and some couples were particularly concerned that they would subsequently be ‘treated differently’ if they revealed their cancer diagnosis.

## Findings

The excerpts below reveal some of the reasoning behind a decision not to disclose their illness to others. One particular man preferred to keep the diagnosis to himself, so as not to concern others:

*'Both of us we have the same mentality. We like to keep certain things. We don't like to make other people worried. That is one thing we have in common.'*

M02

The spouse agreed and noted that their family and friends had their own families and concerns and therefore she did not want to add further worry or distress to them:

*'What is the use, they got their families, and they got their worries.'*

F02

Although one man commented that open disclosure to more distant friends and relatives could have been beneficial, in perhaps receiving additional support beyond his immediate family. However, he suspected that such an approach would lead to others feeling sorry for him and therefore, he did not disclose his diagnosis to them:

*'I know that I could have gotten support but I would rather not be pitied so just my family knows, my kids.'*

M07

Findings indicated that the most couples preferred to limit the exposure of their cancer diagnosis to others. However, this was not always possible for some men who were still involved in work-related activities. As these men had initially undergone daily external beam radiotherapy treatment appointments, they often had to reveal the

## Findings

diagnosis to their superiors or other colleagues due to work absence. Although some of the men therefore had to reveal their diagnosis, they often tried to limit wider exposure and sometimes just selected some pertinent colleagues who they perceived to be 'entrusted' with the diagnosis:

*'I told my immediate boss that works with me and my personal friend so that he can cover for me. I told them not to tell anyone else not even the big boss.....'The friends at work, two of them, the ones that are close, you know. I can trust him and he can trust me, but otherwise, the rest, no.'*

M02

Although most couples preferred only to inform close relatives, four couples (Couples numbered 3, 9, 11 and 14) disclosed their diagnosis to wider friends and relatives, they believed it would facilitate their support network. One man also adopted an open approach to disclosure to encourage other men in his social circle to get tested for prostate cancer and to support others by sharing his experience:

*'I have friends, nearly 5 of them, because it rang a bell. I had a friend of mine we worked together and last time I was telling him: 'Do you wake up at night to go to the bathroom?'. And after that he went to check, and he got diagnosed. So that's why it is nice to talk to people.'*

M09

Couples were often in agreement regarding the disclosure or non-disclosure of the prostate cancer diagnosis to wider friends or relatives. However, data revealed that one spouse (F09) did not agree with the approach adopted by her partner and preferred to keep the

## Findings

diagnosis private.

### 5.2.5. Making a management decision

To make an informed decision about treatment options, most men typically sought information from various sources such as healthcare professionals, the internet and family and friends. However, several men preferred to receive information from previous patients who had undergone the treatment proposed to them by the specialist. During the time of data collection, no specific support groups were available for prostate cancer patients or their families and therefore, the men had to find these individuals themselves, usually via friends or family:

*'Somebody had told me that this particular doctor had passed through this experience, and after me he had about 20 people waiting. When I entered, I told him that I have nothing but that I wanted to speak to him about his experience of the surgery and I think I spend about 45 minutes. He explained to me everything, his experience and what I have to do to prepare myself and I wanted to pay him and he told me: 'no you came here patient to patient' and I came out of that meeting as a lion! That is why I told you that I was prepared for it.'*

M09

Making a treatment-decision was considered challenging as the men were often given a choice between surgery or radiotherapy treatment. For the surgical procedure, men were often offered standard surgical removal of the prostate in the local hospital or the possibility to travel abroad for robotic-assisted surgery. They were therefore put in a particularly challenging position, they had to make a decision not only about their management options but also whether to have it done locally or to travel abroad and spend time away from their family:

## Findings

*'I was given to understand that I had an option, and it is not easy to decide on an option. I mean, it wasn't easy at all. I discussed it with my wife and my son and my daughter - I mean everybody had their opinion to do it in Malta or over in England. I went through a lot of thinking and finally I decided for an operation locally. I didn't want to go abroad. And then they told me, 'Listen there is not such option (sic), and I was angry because there was a delay for nothing.'*

M03

The men varied in their preference to be involved in the management decision. Whereas some preferred to be closely involved in the decision-making process, others were happy to leave the treatment-decision to the healthcare professionals:

*'I had two options there is the operation and there is the radiotherapy. And I asked him: 'if you were my brother what would you suggest?' and he told me I would go for an operation and I was directed for an operation.'*

M09

Although some couples were given time to think prior to making a treatment decision and these couples were given another appointment with the specialist, other couples indicated that they had to make their treatment decision immediately after receiving the diagnosis. These couples were not given any time to consider other potential treatment options and had to give their reply immediately:

*'When the doctor informed us about the treatment in England, he gave us 5 minutes to think about it and he wanted a reply he wanted an immediate reply and*

## Findings

*he talked to some other doctors then and when he came back, he said that they managed to fit me in with another group of 5.'*

M11

For the men, management decisions were most commonly made in conjunction with their direct family, especially their spouses and children. Making a management decision was often difficult for the men and was frequently associated with anxiety and stress. In addition, four of the men (M09, M03, M07, M12) experienced a change in their management plan. Initially, they opted to undergo a surgical procedure, but after making a decision and then waiting for further instruction from the local health department, they were subsequently informed that surgical intervention was no longer appropriate. However, it was not always clear why a change in their treatment plan had been made, and they often indicated a lack of detailed information regarding such a change. It appears that treatment options were often discussed after a positive confirmation of prostate cancer following a biopsy. However, additional investigations are required to inform patients about the most suitable management option such as an MRI scan and bone scan.

The excerpt below revealed how one man (M07) who initially opted to undergo a surgical removal of the prostate abroad, received a phone call from the hospital about the change in his management decision:

*'That was very bad as it was not an option as they first said you go for surgery and I prepared everything I prepared the family and at the last minute and I was just waiting for the day and it was coming in a week time. And then suddenly a phone call it was not going to happen. Why I asked? And they told me we don't*



## Findings

*know. So, I asked who knows and they told me nobody knows. What do you mean nobody knows?'*

M07

Nobody appeared to take responsibility for the apparent change in proposed treatment regime and, even the healthcare profession who contacted the men could not provide a robust justification for the required change. Unfortunately, this understandably caused additional distress and created significant uncertainty regarding the need for such a change.

Another man (M09) who was also informed about the change in his treatment plan felt that he had to start his prostate cancer journey all over again, this had a negative impact on his emotional state.

*'The only time when I felt a bit down was at that moment, I will tell you why. I was sort of directed to go for the operation. Nowadays I am happy with it, but imagine someone tells you that you are going through that door and suddenly someone tells you listen, you cannot go through that door but you have to go through that side window you understand? At that moment I felt a little bit down as I thought that I had to start again from the beginning.'*

M09

The lack of appropriate information also led to some men assuming that their cancer had progressed to a more advanced stage and therefore an operation was no longer a viable treatment option:

*'The initial reaction was very bad and your initial reaction is very bad I thought they were not going to do it because it is too late that the cancer has spread.'*

### **5.3. THEME 2 - NAVIGATING THE PROSTATE CANCER TREATMENT PATHWAY**

#### 5.3.1. Introduction

Going through the prostate cancer journey theme describes the experiences of couples as they progressed through their external beam radiotherapy treatment. All men underwent external beam radiotherapy treatment for localised prostate cancer including: as a standalone treatment option (n=2), in combination with hormone therapy (n=9) and following surgery (n=3). One of the men's greatest concerns appeared to be related to the bladder preparation procedure required throughout their external beam radiotherapy treatment. The men also experienced a range of treatment-related consequences such as genito-urinary side effects, sexual consequences, and body-image concerns. Besides the impact of treatment on the men, this theme also outlines the impact of treatment and related side effects on spouses and the collective impact on couples.

The 'going through the prostate cancer journey' theme includes several sub-themes presented in Table 6. This table demonstrates the relationship between subthemes, including the corresponding codes/nodes and data excerpt examples.

## Findings

Table 6: Overview Theme 2 – Going through the prostate cancer journey including subthemes, codes and nodes created from NVivo and excerpt examples.

<b>Theme 2: ‘Going through the prostate cancer journey’</b>		
<b>Subthemes</b>	<b>Codes / nodes</b>	<b>Excerpt example</b>
Radiotherapy treatment experiences	<ul style="list-style-type: none"> <li>- Positive experiences</li> <li>- Negative experiences</li> <li>- Following the doctor’s advice</li> <li>- Treatment delay</li> </ul>	<p><i>‘But I found out that the staff in radiology were wonderful.’</i> M14</p> <p><i>‘They know you from your name you are not a number you are a person. You are not number 4 you are XX and that makes a difference I find that makes a difference.’</i> F03</p> <p><i>‘I am in your hands you have to tell me what to do as I don’t have any idea.’</i> M02</p> <p><i>‘The period from between when I had the radiotherapy and when I had the interview and before I started the radiotherapy that was a bit stressful.’</i> M05</p>

## Findings

<p>Body Image / Masculinity concerns</p>	<ul style="list-style-type: none"> <li>- Body Image concern</li> <li>- Impact on Manhood</li> </ul>	<p><i>'Not a little bit, a lot I mean imagine buying shirts in September and in October I have to throw them away because this kept on growing.'</i></p> <p style="text-align: right;"><i>M03</i></p> <p><i>'Women they know what is going to happen to them but it doesn't usually affect men and when it happens to you, you feel it inside you.'</i></p> <p style="text-align: right;"><i>M10</i></p> <p><i>'I am worried because I am seeing him putting on weight over here because he hates it. I mean he doesn't say a lot but he always says my tummy my tummy and looking in the mirror. I don't know what he told you. And it bothers me that he is not hundred percent well that as well bothers me.'</i></p> <p style="text-align: right;"><i>F03</i></p>
<p>Radiotherapy side effects</p>	<ul style="list-style-type: none"> <li>- Urine side effects</li> <li>- Bowel side effects</li> </ul>	<p><i>'I cannot keep my urine and I have to run to make it to the toilet. Even when I am inside the car and driving, I sometimes need to go to the bathroom and</i></p>

## Findings

		<p><i>I have to stop and pee.'</i> M04</p> <p><i>'What is worrying me is not his urination it is bowel movement he always gets his pants dirty I mean if we are out, he tells me are my clothes alright?'</i> F03</p>
Hormone side effects	<ul style="list-style-type: none"> <li>- Hot flushes</li> <li>- Increase in weight</li> <li>- Loss of strength</li> </ul>	<p><i>'Other things that I suffer that I experience is the hot flushes which are terrible because I hate heat.'</i> M03</p> <p><i>'I would say he is not doing that bad he is losing sometimes his temper and that is mainly when he is having those hot flushes.'</i> F04</p> <p><i>'I noticed that I am gaining some weight and I had an increase in weight of about 8 kilos.'</i> M10</p>
Psychosexual consequences	<ul style="list-style-type: none"> <li>- Erectile dysfunction</li> <li>- Loss of libido</li> <li>- Sexual aids/issues associated with their use</li> </ul>	<p><i>'I mean no sex and no erection and I mean nothing really, nothing.'</i> M11</p> <p><i>'I mean no erections no ejaculations no sexual urge what so ever but I</i></p>

## Findings

		<p><i>was warned that was going to happen.'</i></p> <p style="text-align: right;"><i>M14</i></p> <p><i>'I mean the doctor did ask us about the pills or the injection but I did not want it.'</i></p> <p style="text-align: right;"><i>M04</i></p>
Psychological impact	<ul style="list-style-type: none"> <li>- Increased sensitivity</li> <li>- avoiding social contacts</li> <li>- more irritable</li> </ul>	<p><i>'I noticed that he has become a bit nervous. He used to be calm but now not always, and maybe it's me too. A bit more edgy you know.'</i></p> <p style="text-align: right;"><i>F01</i></p> <p><i>'I don't think I feel up to talking a lot to people and meeting people I used to love speaking up to people and meeting new people.'</i></p> <p style="text-align: right;"><i>M07</i></p> <p><i>'I used to spend a lot on good nappies you know and then later on good pads big pads I mean I had so much tension during that period.'</i></p> <p style="text-align: right;"><i>F13</i></p>

### 5.3.2. Radiotherapy treatment experiences

As none of the men had any previous experience of radiotherapy treatment, their knowledge and understanding of it was limited and

## Findings

therefore, misconceptions regarding external beam radiotherapy and potential related side effects were common. A common misunderstanding related to expectations about the side effects of radiation on the skin:

*'The radiotherapy, when someone tells you that, you, radiotherapy, you do not know what is going to happen. And I was thinking that I will get burned because of this treatment. So, in your mind, you have a lot things going on.'*

M12

Although the men received information before the start of treatment from the oncologist and treating therapeutic radiographer, some men suggested that further complementary information from previous patients would have been helpful, especially before starting their external beam radiotherapy treatment. Participants felt that this may have helped them to be better prepared for treatment:

*'I spoke to another person who underwent the radiotherapy before I went. and he explained the procedure and that really gave me the courage to go ahead with this treatment and I was prepared for what I was going to face, you know.'*

M09

For most men, engagement with healthcare staff was largely perceived as positive. Men recalled that the staff made them feel at ease and relaxed through the treatment. Similarly, spouses recalled that the personal attention from healthcare staff, such as calling them by their name, engaging in a chat or cracking a joke, helped them during treatment:

## Findings

*'They know you from your name you are not a number you are a person. You are not number 4 you are Mr XX and that makes a difference I find that makes a difference.'*

F03

Although engagement with staff was often perceived as a positive (for example by giving them personal attention), findings suggest that most men found the prostate cancer treatment preparation particularly challenging. For each radiotherapy treatment session, the men needed a rectal enema and had to have a full bladder, they were therefore required to follow an established treatment preparation procedure. The whole treatment preparation procedure commonly took around an hour for each patient. While some men described the enema as generally uncomfortable, the bladder preparation in particular was considered to be challenging. Two men experienced urine leakage in the radiotherapy treatment unit which subsequently brought about feelings of shame and embarrassment:

*'But the thing is the embarrassment, not from the radiotherapy itself as such, but the embarrassment from before. You need to drink all that water and the enema and you trying to hold the urine. And once I had an accident and I did not manage to hold it. And that was very embarrassing for me.'*

M09

The urine leakage often occurred towards the end of their four-week treatment regime, at this point the men started experiencing urinary filling and control effects related to the radiotherapy treatment. Another concern related to the bladder filling procedure was that men were worried that voiding their bladder before treatment, would result in them losing their allocated timeslot and also possibly invalidate the



## Findings

bladder treatment preparation. As the entire treatment preparation could take up to an hour, if they urinated, they needed to start the process again. Some men were also conscious of the impact a delay would have on the men who were waiting outside for their treatment and who also had full bladders:

*'I used to get worried in case I needed to go to the toilet. Because I don't want to stop halfway and then you have to go for my sake and for his sake and for everybody, you know sometimes you have people outside waiting.'*

M02

As the treatment often typically took four weeks or more to complete, some men did comment about a 'community feeling' with fellow patients with prostate cancer:

*'I mean we had a good laugh out there because you are meeting the same kind of people when you are going through it, I mean when we used to get the water, I asked them what kind of flavour do you have today? So, we try to lighten the mood for each other you know.'*

M14

Some of the men exchanged information about their experiences with others and some even remained in contact with other patients after completing their prostate cancer treatment.

Not all men were aware of the nature of treatment-related side effects, for example, the expected timing and/or the extent of subsequent personal impact. Although they often recalled having received information about potential side effects before the commencement of

## Findings

treatment, it appears that they were not always aware that side effects could occur for several months following the completion of the treatment or how long such effects might subsequently last:

*'We had a meeting before, obviously before the commencement of treatment. And they told us the possible consequences, but I always thought that these possible consequences were during the treatment. I was not aware of things to come out five months after. Nobody said, 'Listen, this may take a period of 1 year or 2 years.' Nobody said that this might happen when you take this radiotherapy. It was logically for me - I mean, today was the last day of the therapy and thank God I feel fine. I was not aware that the problems will start afterwards.'*

M07

### 5.3.3. Radiotherapy side effects

The men experienced a range of acute treatment-related consequences following their external beam radiotherapy treatment. The most commonly experienced radiotherapy side effects were urinary side effects, and these are further presented in the following section.

#### 5.3.3.1. Urinary related side effects

Urinary urgency, hesitancy and nocturia were commonly experienced by most men. Several men also experienced urinary leakage, and this often had a negative impact on their emotional wellbeing:

*'At night when I am going to the bathroom, it is difficult, I do, but it is slow it takes ages at night than after one or two I will be almost normal. Although sometimes it*

## Findings

*happens more than once that I need to go to the toilet quickly and I really have to run otherwise I won't manage. And it happened not very often but more than once that I lost control of my bowels and my urine. I mean this happens quite rarely maybe 5 or 6 times but normally, I hold it and right now I need to go to the toilet.'*

M03

Findings suggest that urinary urgency appeared to be a notable concern, it seemed to adversely affect couples' social functioning. In particular, spouses were often concerned about their loved ones' urinary side effects, and it adversely affected their emotional and social wellbeing:

*'A bit of the social element and a bit of adjustment for example I cannot sleep properly at night because he has to wake up all the time and I have to ask if he is fine. I have to you know when I am driving, I have to be patient with him as sometimes he is telling me to drive faster as he needs to go to the toilet you know.'*

F04

These urine related side effects often had a negative emotional impact on the men and caused anxiety, mainly when a toilet was not nearby. To deal with the stress and uncertainty caused by these side effects, several couples subsequently changed their social activities. For example, places without bathroom facilities and/or places requiring long travelling times were generally avoided, with many couples also expressing concern about visiting places they were not entirely familiar with:

## Findings

*'What I mean is that the side effects have affected our social life. For example, I cannot keep my urine and I have to run to make it to the toilet. Even when I am inside the car and driving, I sometimes need to go to the bathroom, and I have to stop and pee.'*

M04

It was also noted that for some men, behaviour modification related to urinary side effects could lead to social isolation, which in turn could further exacerbate their emotional well-being:

*'I would rather not go out and this because of the bathroom and because I don't think I feel up to talking to a lot to people and meeting people.'*

M07

### 5.3.4. Hormone specific side effects

Most of the men (n=9) in this study underwent a combination of external beam radiotherapy and hormone treatment and they experienced a range of hormone related side effects, including weight gain, enlarged breast tissue, loss of muscle strength and hot flushes:

*'Well, I noticed some hair loss I noticed that before I had more hair and I noticed that I am gaining some weight and I had an increase in weight of about 8 kilos. Last time I asked and they told me that it could be one of the side effects of the treatment.'*

M10

## Findings

Findings suggest that the hot flushes and increase in weight were particularly bothersome for some men:

*'From the side effects that bothered me afterwards that I put on weight because I started the hormone treatment. I mean, I have put on a bit of weight and my breast grew a little bit. That bothered me more than some of the other things, as these other things I was expecting in a way.'*

M05

Spouses also commented on the negative impact that hormonal side effects had on the mood of their partners. For example, it was noted that hot flushes adversely affected couples' social wellbeing:

*'I would say he is not doing that bad he is losing sometimes his temper and that is mainly when he is having those hot flushes and that he can't go out that much as he liked to go out.'*

F04

### 5.3.5. Psychosexual consequences

Another commonly experienced side effect of prostate cancer treatment related to psychosexual consequences. Men noted changes in their sexual functioning such as erectile dysfunction and loss of libido, which subsequently had a negative impact on their emotional state:

*'Because I feel, I don't feel. As I said, it bothers me I don't get an erection. It does. It used to even more, but now I got used to it. It is a change, a big change'*

## Findings

*and yes it used to affect my mood when I think about it.*

*M03*

Although these sexual changes impacted both men and their spouses, it appeared that the spouses sometimes found it easier to accept the sexual changes. Several of the spouses indicated that because they were in their menopause, sex was less of a priority to them, and therefore it could have been easier for them to accept these changes:

*'For me it doesn't really affect me as I am in the menopause and you know I was already used to it.'*

*F10*

Following this remark, the man (M10) noted that menopause only happens to women, for men, sexual changes or disruptions are not expected and this could therefore negatively impact on their emotional wellbeing:

*'Woman they know what is going to happen to them, but it doesn't usually affect men and when it happens to you feel it inside you.'*

*M10*

### 5.3.6. Body image / Masculinity concerns

Findings suggest that certain side effects (for example urinary side effects) may be easier for men to accept compared with some of the notable side effects associated with hormonal treatment. Hormonal

## Findings

side effects including weight gain, breast enlargement, and hot flushes, appeared to impact on men's self-image and masculine identity and therefore presumably also the couples QoL. In particular, some of the men noted that they became more self-conscious about their appearance and this adversely affected their emotional wellbeing:

*'I gained some weight and I would like to lose it. I mean it makes you more self-conscious about yourself I guess, which I never was before.'*

M05

Several of the men commented that they had 'lost their manhood' as a result of treatments and some noted a sense of grief and loss associated with these changes:

*'I mean part of the man, half of him is death with this type of treatment.'*

M10

In addition to the physical changes caused by prostate cancer treatment, the negative impact of the treatment on men's sexual functioning further eroded their masculine views or identity. One man noted that he no longer views himself as a man due to the changes caused by prostate cancer treatment:

*'That means that your sex drive is gone you cannot longer function as a man in that department so when is a man not a man? And I am not a man.'*

M14

The negative impact of the treatment on men's wider self-image or masculine identity was also noted by their spouses, this had a negative

## Findings

impact on their emotional well-being, functioning and presumably their level of sexual intimacy:

*'I am worried because I am seeing him putting on weight over here because he hates it. I mean he doesn't say a lot but he always says my tummy my tummy and looking in the mirror.'*

F03

### 5.3.7. Psychological Impact

One of the greatest consequences of prostate cancer treatment appeared to be related to the psychological consequences. Throughout the prostate cancer pathway, both men and their spouses reported considerable psychological impact as a result of their diagnosis and treatment for prostate cancer:

*'It gave me a shock originally not the treatment but the whole thing the cancer thing. it gave me a shock cause you think is he going to die?'*

F03

Some men believed that the prostate cancer treatment was not only a physical challenge, but also a psychological challenge that they had to face:

*'I was upset I wasn't angry I was just upset you just have to accept in life what comes and it's how you handle it in your mind. Because with the cancer it is as much a mental thing as it is a physical thing.'*

M14



## Findings

It was even noted that some men appeared to regret their decision to undergo the prostate cancer treatment, they felt that the treatment may have caused more harm than benefit to them:

*'I don't feel happy at all. I mean I feel deep down that I am not doing something that have been of benefit you know health-wise and I cannot do them as I used to them you know. I will try to do them later on, reactivate my past but.....ha-ha we have to see.'*

M06

Although some of the men commented that the experience had made them 'mentally stronger', they perceived that they had managed to overcome the illness and its consequences whilst others appeared to suffer more from the psychological impact. For example, one man (M07) commented that the treatment had made him more sensitive which he found difficult to comprehend. He was offered anti-depressant medication following the completion of prostate treatment to help with the psychological consequences:

*'In my case it did not work out that way my doctor insists that I take calming pills but until now I have managed not to take them'*

M07

Besides the direct impact on the men, the treatment also adversely affected spouses. For example, supporting and taking care of their partner was, for some spouses, particularly challenging. This could have a negative impact on their emotional wellbeing especially when perceived support was lacking:

*'It is not the physical aspect or for example changing the nappies or the catheter it is more the*

## Findings

*psychological aspect the support you know that you have someone who will be checking on you how everything is going you know.'*

F13

### **5.4. THEME 3 – DEALING WITH CHANGING HEALTH STATUS**

#### 5.4.1. Introduction

Men and their spouses reacted and approached the diagnosis and treatment of prostate cancer from different perspectives. This appeared to be due to the fact that men are the ones who are diagnosed with prostate cancer and have to undergo treatment whilst the spouses then play a key role in supporting their husbands throughout this process. In theme 3 - Dealing with changing health status, the male-specific approaches to dealing with the consequences of prostate cancer treatment are presented. Interpretation of data suggested that most men preferred to deal with the consequences of prostate cancer on their own. In addition, most men tried to 'keep up the appearance' in front of others, particularly spouses and/or other family members. For some of the older men, many of the changes associated with prostate cancer treatment (for example sexual dysfunction) appeared to be easier to accept due to their advanced age.

The different sub-themes and strategies that the men adopted are presented in Table 7, they are further presented in this section. This table demonstrates the subthemes, including the corresponding codes/nodes and data excerpt examples.

## Findings

Table 7: Overview Theme 3 – Dealing with changing health status including subthemes, codes and nodes created from NVivo and excerpt examples

<b>Theme 3: ‘Dealing with changing health status’</b>		
<b>Subthemes</b>	<b>Codes / nodes</b>	<b>Excerpt example</b>
Dealing with prostate cancer alone	<ul style="list-style-type: none"> <li>- Not involving others</li> <li>- Can personally handle the situation</li> </ul>	<p><i>'I told them listen this is something which affects only me so leave it up to me I can cope with it and I managed to do it on my own that is my character.'</i></p> <p style="text-align: right;">M09</p> <p><i>'I couldn't be in peace but I didn't let anybody else know I just kept it to myself I locked it away.'</i></p> <p style="text-align: right;">M14</p>
Minimising Impact and hiding emotions	<ul style="list-style-type: none"> <li>- Minimising impact</li> <li>- Downplay the consequences</li> <li>- Keeping up appearances</li> <li>- Hiding emotions</li> </ul>	<p><i>'It is something that you carry with you but I don't let it affect me I still do what I plan to do and whatever.'</i></p> <p style="text-align: right;">M05</p> <p><i>'We have managed to overcome the negative effects alright I have these limitations but we managed them I believe.'</i></p> <p style="text-align: right;">M03</p> <p><i>'I am trying to keep up a strong appearance in front of everyone even when I</i></p>

## Findings

		<p><i>am not happy, I try to smile.'</i></p> <p style="text-align: right;">M12</p> <p><i>'I was putting on a facade I was put on a front just to keep everyone else a sense of normality.'</i></p> <p style="text-align: right;">M14</p>
Using Humour	<ul style="list-style-type: none"> <li>- Humour</li> <li>- Making a joke</li> </ul>	<p><i>'I cannot keep my urine and I have to run to make it to the toilet. Even when I am inside the car and driving, I sometimes need to go to the bathroom and I have to stop and pee.'</i></p> <p style="text-align: right;">M04</p> <p><i>'What is worrying me is not his urination it is bowel movement he always gets his pants dirty I mean if we are out, he tells me are my clothes alright?'</i></p> <p style="text-align: right;">F03</p>
Changes related to age	<ul style="list-style-type: none"> <li>- Getting older</li> <li>- Impact of age</li> </ul>	<p><i>'We are both slower as we were used to be and we recognize that but it's not because of the cancer is because of the age.'</i></p> <p style="text-align: right;">M05</p> <p><i>'I look also at my age and I am not the youngest anymore.'</i></p>

#### 5.4.2. Dealing with prostate cancer alone

Several men preferred to deal with the diagnosis and treatment on their own and therefore did not want their partner or other family members with them whilst attending treatment sessions. Typically, they believed that they were capable of dealing with the illness independently and, by doing so, they felt that they were also protecting their partner and family from their illness:

*'I don't want them with me because they are so worried. And I told them, 'Listen, this is something which affects only me. So, leave it up to me I can cope with it. 'And I managed to do it on my own - that is my character.'*

M09

These men were concerned that the prostate cancer diagnosis and treatment could be detrimental to their independence. In particular, it was noted that the physical changes caused by prostate cancer, such as the lack of stamina and urinary related side effects, could adversely affect their independence. By dealing with cancer on their own, the men felt that they were better able to 'take control of their illness':

*'I don't like it. How do you say it. We are independent sort of and I don't want them to come for 4 or 5 hours and if someone is with me, I get more nervous'*

M02

Although some of these men preferred to deal with the prostate cancer alone or independently, some men did acknowledge that their spouses were there to support them during the journey:

## Findings

*'I mean my wife has been really quiet about it I mean occasionally she will sit down quietly next to me and she ask me if I am, ok? Especially when I go through the rough patches and especially when I have some aches and pains but I have to learn to live with it I just proceed and carry on like normal.'*

M14

### 5.4.3. Minimizing impact and hiding emotions

The men appeared to downplay or minimise the impact that the prostate cancer treatment had on them in order to demonstrate their ability to cope with the deleterious treatment consequences. They seemed to maintain a stoic mindset when faced with the negative effect of the cancer by trying to 'take control' of their condition:

*'It is something that you carry with you but I don't let it affect me. I still do what I plan to do and whatever'*

M05

The men were often reluctant to share their emotions with their spouse and/or family throughout their treatment and often tried to maintain a 'sense of normality'. However, several acknowledged the negative impact their condition had on their emotional well-being:

*'I was really down and it impacted very badly on my life. Everything seemed really black and I was putting on a facade. I was put on a front just to keep everyone else a sense of normality. And I knew inside, that you know, until I got the final diagnosis and the course of treatment I was going to take, I couldn't be in peace. But I didn't let anybody else know - I just kept it to myself. I locked it away.'*

#### 5.4.4. Changes related to age

Prostate cancer treatment can result in physical (for example loss of strength), psychosocial (for example reduced social interactions) and sexual (for example erectile dysfunction) consequences which can have a profound impact on men's functioning. Data interpretation suggests some differences in relation to the age of the men at diagnosis, particularly when dealing with the physical side effects of treatment (for example loss of strength and/or sexual changes). Although this study included men in a relatively similar age group (64-74 years), more of the younger men (64-69 years) appeared to struggle with such changes, when compared with the relatively older men (70-74 years). Findings revealed that the younger men considered themselves to be of an age where they should still be able to perform certain physical (for example going for a walk) and sexual (for example maintain an erection) activities. However, for some of the men, the prostate cancer treatment related side effects resulted in a misalignment of their perceived self-image, which negatively impacted their emotional functioning:

*'No, I never imagined it. The thing is, listen I am not that old either. I mean 64 is a relatively medium age where one can still enjoy life....I am usually a very active person very active another thing which is also very important I think I am tired all the time from the time I wake up until the time I go to sleep I am tired. I can't walk because I am too tired sometimes, I don't even walk in a straight line is everybody like that? '*

It appears that the younger men (64-69 years) felt that they were still at a relatively young age and perceived the physical changes such as

## Findings

the loss of strength or fatigue having a negative impact on their enjoyment of life. Conversely, some of the older men (>70 years), appeared to accept these changes more easily, possibly due to their perceived advanced age:

*'They explained that your sex life practically disappears and from the side effects that bothered me afterwards that I put on weight because I started the hormone treatment. I mean I have put on a bit of weight and my breast grew a little bit that bothered me more than some of the other things are these other things I was expecting in a way and at our age it wasn't a major issue I mean it was a bit annoying you know I think it would be terrible for someone who is much younger because it does affect one's life.'*

M05

It can be suggested that the men related the changes not just to the treatment but also to their age. Although most of the older men appeared to have less concerns with the changes caused by prostate cancer treatment, one older man found it particularly difficult to accept these sexual changes. However, this man (M04, 70 years) had a younger wife (40 years) and had an active sexual life before treatment commenced. Therefore, it is possible that these factors could have made it more difficult to accept the changes brought about by prostate cancer treatment:

*'Maybe you didn't realise exactly what I was saying but until I was 69, I was still sexually active I am not saying that I was active when I was younger but three times a week then I started this treatment and last time I was speaking to Dr X. He told me that maybe after I stop with the injections maybe it will come back.'*



## Findings

*I am not losing hope completely but I don't know how it can be done I told him but don't expect anything. It's my wife I mean my problem is not my wife my problem is that I am worried about my wife something I never wished it would happen but it did.'*

M04

## **5.5. THEME 4 – BALANCING DIFFERENT SPOUSAL ROLES**

### 5.5.1. Introduction

Findings suggest that spouses were the primary source of social support for the men. Besides supporting their husbands, spouses also dealt with the impact of the condition and treatment-related side effects, their own emotions and the need to maintain other tasks and commitments. The theme 'Balancing different spousal roles' captures the impact of supporting their husbands during the process.

Several men did not involve their spouses in the prostate cancer treatment and/or recovery, therefore some spouses were excluded from the recovery process of their husbands. Others had a more prominent role in supporting their husbands such as involving them in activities or events as a form of distraction, encouraging them to complete treatment and providing emotional support, when required. Providing support to their husband and dealing with the impact of prostate cancer themselves was emotionally challenging and some spouses tried to hide their emotions during the process in order to show resilience to their husband.

An overview of these different approaches can be found in Table 8 and is further presented in this section. This table demonstrates the

## Findings

subthemes, including the corresponding codes/nodes and data excerpt examples.

*Table 8: Overview Theme 4 – Balancing different spousal roles including subthemes, codes and nodes created from NVivo and excerpt examples*

<b>Theme 4: 'Balancing different spousal roles'</b>		
<b>Subthemes</b>	<b>Codes / nodes</b>	<b>Excerpt example</b>
Not involved / side-lined	<ul style="list-style-type: none"> <li>- Not involved</li> </ul>	<p><i>'He always went alone that is why I told you that I don't know what I can tell you because he was always on his own.'</i></p> <p style="text-align: right;">F02</p>
Supporting husband	<ul style="list-style-type: none"> <li>- Accompanying during treatment</li> <li>- Involving husband in activities</li> <li>- Encourage husband</li> <li>- Being there for partner</li> </ul>	<p><i>'I try to involve him to give him something to do learn how to cook because I cook every day so if you learn how to cook you have something to do.'</i></p> <p style="text-align: right;">F03</p> <p><i>'The most important thing is that he gets discouraged and you have to push him you know and shake him a bit and he is alright.'</i></p> <p style="text-align: right;">F05</p> <p><i>'I just let him do what he wants for example if he wants to drink this or do that, I let him do it. I am</i></p>

## Findings

		<p><i>just here to remind him and to support him.'</i></p> <p style="text-align: right;"><i>F04</i></p>
<p>Setting personal feelings aside</p>	<ul style="list-style-type: none"> <li>- Setting personal feelings aside</li> <li>- Put on a brave face</li> </ul>	<p><i>'Although I felt bad myself, I had to be supportive to him because he was passing through a bad time you know we had to pass it through together.'</i></p> <p style="text-align: right;"><i>F01</i></p> <p><i>'I came every day and never complained of anything although I didn't feel like all the time.'</i></p> <p style="text-align: right;"><i>F03</i></p>
<p>Emotional impact / dealing with emotions</p>	<ul style="list-style-type: none"> <li>- Concerned about husband</li> <li>- Worried/distressed</li> <li>- Information seeking to deal with emotions</li> <li>- Getting support from friends</li> </ul>	<p><i>'I am worried about the he might feel pain or something like that. But I never it never crossed my mind and I searched a lot about prostate cancer online so I am not that worried and it appears to be a normal sickness for older guys.'</i></p> <p style="text-align: right;"><i>F04</i></p> <p><i>'I mean that when he goes to the toilet that he sees blood. That he has</i></p>

## Findings

		<p><i>to get up at night to go and pass urine but that he cannot do it. Like that is not a normal thing no. Those things I worry like if something else happens to him.'</i></p> <p style="text-align: right;"><i>F03</i></p> <p><i>'He is a fighter it affected me more than him. Mentally you know all the time thinking about it.'</i></p> <p style="text-align: right;"><i>F12</i></p> <p><i>'Reading till 2 or 3 in the morning on the internet looking around what am I going to do what can they give him what kind of treatments are out there because I am like that I have to know everything from A to Z what is going to happen.'</i></p> <p style="text-align: right;"><i>F12</i></p> <p><i>'With my friends I discuss everything absolutely everything and with my friends I can speak about everything. With him not all he talks about is</i></p>
--	--	---

## Findings

		<i>football.'</i>	F02
--	--	-------------------	-----

### 5.5.2. Not involved or side lined

Not all spouses had an active role during their husbands' prostate cancer pathway. As discussed earlier, some men preferred to deal with their diagnosis and treatment independently and excluded their spouse from the process. Spouses noted a lack of communication with their husbands and were therefore often minimally involved in the treatment and recovery process of their husbands, consequently they were not aware of the treatment or the associated side effects:

*'For me it was just the same. We don't talk a lot so I don't really know what is happening. But since he said that he was doing alright and it's not bad, that's it. Day after day. Probably a lot of couples are like us and they don't talk about it. If he tells me he is alright. 'Do you want me to come with you to hospital?' No. So you don't go. He comes home. 'How was it?' OK. And that's it. It is finished.'*

F02

Although several of the men adopted an individual approach and did not involve their spouses in the process, it remains somewhat unclear what impact this had on their spouses. Only one of the spouses was openly vocal during the interview, she expressed her views on the situation and appeared to accept her lack of involvement. She revealed that they were used to a more individual approach as this was common in their relationship:

*'After I think so many years of marriage...haha.. Ups and down and more down than ups then you sort of go in your own way.'*

### 5.5.3. Supporting their husbands

Several spouses were more closely involved in the prostate cancer journey of their husbands, they tried to support them in a variety of ways such as accompanying them to treatment, involving them more in social activities and providing support and encouragement.

As external beam radiotherapy treatment was delivered daily over a minimal four-week period, several spouses accompanied their husbands during all hospital appointments and treatment sessions. By accompanying their husband, spouses were better able to provide relevant support throughout the treatment process. However, providing such support was often emotionally challenging:

*'I mean I came with him every day sometimes we took about 2 hours because by the time he had the enema and he goes to the toilet and the water and he misses his turn because they are very punctual. I came every day and never complained of anything although I didn't feel like all the time.'*

F03

For some spouses, other commitments such as employment or taking care of other dependents (for example grandchildren) prevented them from accompanying their husband for all treatment sessions:

*'I mean even during the treatment he used to walk and he used to go with the bus himself you know and, in the beginning, I used to go with him but I needed to go abroad to take care of my grandson so I had to teach him how to take care of himself.'*

## Findings

F13

Several women noted a change in their husbands' emotional wellbeing as a result of the impact of prostate cancer treatment and in some cases adopted temporary distraction strategies such as involving them in social events:

*'When I see him and he is in a bad mood, I tell him: 'Listen, I need to go to shop over there, like in Gozo. In Gozo? Yes, I need to go to Gozo.' I try to invent something to make him go out or phone up friends and have a coffee.'*

F03

Providing support to their husbands whilst also dealing with the impact of prostate cancer themselves was considered to be a challenge and several spouses noted the negative impact this had on their emotional well-being.

### 5.5.4. Emotional impact on spouses

Supporting their husband throughout the prostate cancer experience was often emotionally challenging for spouses. In particular, several were worried when their husband noted blood in their stools or when they urinated frequently. These changes were considered to be abnormal and although they were aware that this may be a result of treatment, such experiences left the women uncertain about their husbands' physical health:

*'I mean that when he goes to the toilet that he sees blood. That he has to get up at night to go and pass urine but that he cannot do it. Like that is not a normal thing, no? Those things I worry like if something else happens to him.'*

## Findings

F3

To deal with the emotional impact, spouses used different strategies such as seeking emotional support from friends or relatives and health information seeking. In particular, health information seeking was adopted to potentially alleviate some of the distress they were experiencing as well as being a resource for their partner who sometimes did not engage in information seeking. Spouses typically used the internet as their main information source regarding treatment options, side effects and outcomes.

*'Reading till 2 or 3 in the morning on the internet looking around what am I going to do what can they give him what kind of treatments are out there because I am like that, I have to know everything from A to Z what is going to happen.'*

F10

Spouses noted that although healthcare professionals were available to provide information and advice throughout treatment, this was often focused and directed towards the men. It appears that a lack of attention was given regarding the impact on spouses, particularly following the completion of the treatment. One spouse also noted that the support for her was lacking:

*'That is why I told you that there needs to be more support I mean even if we have any questions, we don't know who we can ask at this moment. At least there is someone who can phone up or something if it is not him it can be me as like you mentioned before it can impact on both of us.'*

F12



## Findings

Support may be particularly relevant for women following the completion of the prostate cancer treatment. During treatment, spouses were often busy taking care of their husbands. They also had other commitments and therefore had less time to process and respond to their new situation. Following the completion of treatment, spouses were able to better reflect on their experience which perhaps affected their emotional wellbeing. In fact, one woman commented that she got depressed following the completion of prostate cancer treatment:

*'I mean, I am nervous. I mean, my life changed because with this thing, I can't do the things I used to do before. And I got a depression after he got this, as it doesn't hit you during the whole process but it happens after.'*

F13

A common approach adopted by several women included hiding 'their true feelings or emotions from their partner and this is presented further in the next section.

### 5.5.5. Setting personal feelings aside

A common approach adopted by spouses was to focus on their husband's wellbeing and recovery, which was often at the expense of their own well-being:

*'Although I felt bad myself, I had to be supportive to him because he was passing through a bad time you know.'*

F01

## Findings

Some spouses tried to hide their emotions from their husband and family, perhaps because they wanted to protect and better support them:

*'I couldn't talk like. I would know what he will be suffering from you know. I wanted to cry like but I was trying to put on a brave face so that I would give courage to my husband you know.'*

F13

## 5.6. THEME 5 - REFRAMING THE RELATIONSHIP

### 5.6.1. Introduction

Although the men and their spouses appeared to react to and approach the prostate cancer diagnosis and treatment from a different perspective, several approaches were identified in this study that may enhance or be detrimental to marital relationships as a result of prostate cancer treatment. The 'reframing the relationship' theme encompasses the different approaches used by men and women when dealing with the consequences of prostate cancer treatment. An important aspect for a shared or couples' coping strategy identified in this study, is the use of different communication styles adopted by the individual members of the couples. Although some couples were able to voice their concerns to each other and developed a form of shared coping strategy, others appeared to follow a more individual approach when dealing with prostate cancer. In particular, couples that approached the disease from a 'shared' perspective appeared to collectively adapt better to the changes resulting from cancer.

## Findings

The different approaches that were shared between the couples are presented in Table 9. This table demonstrates the subthemes, including the corresponding codes/nodes and data excerpt examples.

*Table 9: Overview Theme 5 – Reframing the relationship theme including subthemes, codes and nodes created from NVivo and excerpt examples*

<b>Theme 5: 'Reframing the relationship'</b>		
<b>Subthemes</b>	<b>Codes / nodes</b>	<b>Excerpt example</b>
Communication	<ul style="list-style-type: none"> <li>- Avoidance</li> <li>- Lack of communication amongst couples</li> </ul>	<p><i>'We don't talk a lot so I don't really know what is happening. But since he said that he was doing alright and it's not bad that's it. Day after day.'</i></p> <p style="text-align: right;"><i>F02</i></p> <p><i>'We never really sat down or talked much about it or whatever we knew about it we talked when we had to go to the oncologist or whatever but otherwise it was business as usual.'</i></p> <p style="text-align: right;"><i>P05</i></p>
couples coping strategies	<ul style="list-style-type: none"> <li>- Making time for each other</li> <li>- Engage in new activities</li> </ul>	<p><i>'We survived it quite well we still went on holidays. In fact, we decided we should go on a holiday. We didn't change our</i></p>

## Findings

	<ul style="list-style-type: none"> <li>- Couple resilience / marriage strength</li> <li>- Distraction</li> <li>- Religion</li> </ul>	<p><i>lifestyle we kept on with life.'</i></p> <p style="text-align: right;">F03</p> <p><i>'I am happy to say that we have managed to live through it the best we can there are things that are missing but then you have to look at the big picture and do what is best you choose we discussed together the situation when it was developing.'</i></p> <p style="text-align: right;">M03</p> <p><i>'We had to pass it through together that what marriage is for. for goodness for health and in sickness and in health that what is marriage is for.'</i></p> <p style="text-align: right;">F01</p>
<p>Comparing and contrasting</p>	<ul style="list-style-type: none"> <li>- Compare to pre-treatment situation</li> <li>- Compare to previous struggles</li> </ul>	<p><i>'My recovery will start when I start feeling stronger when I can go for a walk, I mean I used to go for a walk I don't know how long 7km or 9km every</i></p>

## Findings

	<ul style="list-style-type: none"> <li>- Compare others to</li> </ul>	<p><i>morning now I can barely go down the block right. Recovery is not on the cards at the moment.'</i></p> <p style="text-align: right;">M07</p> <p><i>'Thank God it went all good for him as there are others who have it much worse than he.'</i></p> <p style="text-align: right;">F01</p>
<p>Couples supportive care needs</p>	<ul style="list-style-type: none"> <li>- Information needs pre-treatment</li> <li>- Support following treatment</li> <li>- Lack of time with consultant</li> </ul>	<p><i>'I went to the UK and when they informed me that I didn't need an operation at this time I was thinking a lot about it and I was wondering who was right and who was wrong? The Maltese doctors or the doctors in the UK?'</i></p> <p style="text-align: right;">M12</p> <p><i>'Well, when you ask something, they will answer, but it will be limited and I wanted more details.'</i></p> <p style="text-align: right;">M04</p> <p><i>'Actually, I thought that that sort of thing can only happen</i></p>

## Findings

		<i>during the radiotherapy but that is not the case it happens afterwards.'</i> M07
--	--	--

### 5.6.2. Communication

Some couples appeared to discuss their concerns openly with each other, whereas others seemed to avoid such open discourse:

*'We don't really discuss. That is the way in our house, sort of. We don't talk too much. Even when I have sometimes an appointment in hospital, I don't even tell him. That is why.'*

F02

Different communication styles were identified, some couples appeared to avoid open communication in general whilst others specifically avoided cancer-related discussions and instead tried to maintain a 'business as usual' approach by avoiding 'the elephant in the room':

*'We never really sat down or talked much about it or whatever we knew about it. We talked when we had to go to the oncologist or whatever, but otherwise it was business as usual.'*

M05

Findings revealed that avoidance of cancer-related discussion appeared to be commonly adopted by most couples. Furthermore, couples that did disclose their diagnosis to wider friends and relatives,

## Findings

noted that their family and friends also commonly avoided cancer-related discussions and often did not mention the word 'cancer':

*'I mean, really nobody mentioned it. And those from the family that do know, they don't really mention it. They don't even mention the name, they don't have to go over and over it, you know? Maybe when you are talking, I would just mention that I went through it and that is that. There is no need to harp on the same note.'*

M06

Communication issues were also noted when there was a misunderstanding between treatment side effects and spouses' understanding of such side effects:

*'I can tell you that my wife and family could not believe it they cannot understand how I cannot go for a walk they cannot understand why I should prefer to sit down or do things.'*

M07

### 5.6.3. Couples' coping strategies

Couples were all in long-lasting marriages (the mean length of marriage was 36 years), several highlighted the importance of marriage and how it enabled them to cope with the negative consequences of treatment. For example, several couples often used the plural 'we' to emphasize their shared experience of the prostate cancer journey:

*'We had to pass it through together. That is what marriage is for. For goodness, for health and in sickness and in health - that is what marriage is for.'*

## Findings

F01

However, other couples did not appear to have a shared understanding and perceived it as an individual concern, thereby adopting a more individual approach of coping with the experience. Such an approach was largely driven by the men because they often preferred to deal with the consequences independently:

*GvD - 'How did you cope as a couple with the consequences of prostate cancer?'*

*'I would say it is more an individual thing. I mean it is mental strength, is very important to get through it. The advice I will give to anybody is to don't give up just keep on fighting.'*

M14

Couples that approached the disease from a 'shared perspective' appeared to be more able to support each other throughout the process:

*'I am thankful that I have this one (wife). Because it is important. It can destroy you, this thing can destroy the relationship between a man and a woman. Definitely. It can have a very negative effect but thank God it didn't. And I am happy to say that we have managed to live through it the best we can. There are things that are missing, but then you have to look at the big picture and do what is best.'*

M03

Several strategies were commonly adopted to deal with the consequences of prostate cancer, such as purposeful engagement in



## Findings

shared activities or events. For example, several couples booked a holiday during their treatment, which allowed them to have a shared goal and presumably 'a reward' following completion of treatment. As the couples were faced with a range of negative consequences associated with treatment, the planning and organisation of a holiday enabled the couples to have something positive to look forward to. Furthermore, it could be seen that such approaches require close collaboration between the couples, it could also be beneficial to their adjustment to prostate cancer:

*'Yes, we went for a holiday and we booked another holiday again, as we are going to Italy.'*

F10

*'Yes, whatever happened in life, you have to move on.'*

M10

A commonly adopted coping strategy identified in my study was the use of distraction. For example, some men continued to work, they highlighted the importance of their work as it distracted them from thinking about their illness. Working or employment also allowed these men to maintain their social contacts and helped them in their efforts to cope with some of the negative consequences of prostate cancer treatment:

*'I mean even my children used to tell me don't go to work and I used to tell them leave me alone as I know how I feel. Listen because if you go to work you know you meet people you talk and time passes imagine sitting at home and waiting for the time that you can go for the treatment. Listen if your life is busy and occupied with work and other things you have less*

## Findings

*time to think about it and things pass quick and that is what I believe.'*

M09

Open communication was identified as an important aspect for a shared adjustment and some couples noted that that the prostate cancer experience had brought them closer together. Although some couples were no longer able to express their love and affection as they had done prior to diagnosis and treatment, they were able to achieve a closer interpersonal connection with each other:

*'Mind you, we are sort of to say, closer'*

GvD – *'Closer- what do you mean?'*

*'Closer to each other I mean closer to take care of each other but without any sexual contact'*

M08

Another aspect that helped couples adjust so that they could cope with the negative consequences included praying and attending mass and religious activities:

*'Listen I will tell you we as I said I am a believer and I believe that there were a lot of people praying for me and that helps. Knowing that you get that support morale support all about you and it gives you courage and it keep you strong.'*

M03

Besides the positive influence that praying had on their ability to gain support, religion or religious beliefs also allowed some couples to

## Findings

believe God controlled their destiny and it was therefore not within their control:

*'I leave it in God's hands if it happened it happens. I mean I just carry on that is just been my way of life.'*

F05

### 5.6.4. Comparing and contrasting

A commonly used couples' coping strategy was to compare and contrast their prostate cancer experience with other relevant life events. For example, such an approach was often used to try and put their condition into perspective and emphasise the relatively positive outcome of their prostate cancer diagnosis:

*'Thank God it went all good for him, as there are others who have it much worse than he.'*

F12

Another approach included appropriate comparisons with previous challenges in life. For example, several couples compared the prostate cancer experience with other previously comparable struggles, such as a major accident or other chronic medical conditions. Consequently, some couples often perceived prostate cancer as less of a relative threat and were therefore more confident of being able to cope with prostate cancer:

*'I have been through a lot. I was in the civil service and due to a work-related incident, I had a lot of injuries in my legs. And I spend three months in hospital without moving in bed, because there was the possibility of losing my legs and thankfully I didn't. I*

## Findings

*have been through a lot of things and somehow, I think that was the most difficult time in my life.'*

M03

Findings suggested that comparing and contrasting relevant experiences was also adopted by some couples to compare their physical and emotional wellbeing following treatment with their pre-treatment functioning. Some men compared their physical functioning with their pre-treatment functioning, these men were often struggling in their recovery process following prostate cancer treatment. One man (M07) in particular, appeared to suffer from several physical changes associated with treatment such as a loss of strength and lack of stamina which prevented him from performing activities such as going for a walk in the morning:

*'My recovery will start when I start feeling stronger, when I can go for a walk. I mean, I used to go for a walk, I don't know how long, 7km or 9km every morning. Now I can barely go down the block, right. Recovery is not on the cards at the moment.'*

M07

Several areas were identified where couples wanted additional support, and these are presented in the following section.

### 5.6.5. Couples' supportive care needs

The couples highlighted several areas in which they required additional support and information from healthcare professionals. Although the information and support available during the treatment of prostate cancer was often perceived as adequate, the pre- and post-treatment phase were identified as areas which would benefit from further relevant information and clinical support.

## Findings

As outlined in Section 5.2.5, several men had an enforced change to their original management plan, some commented that the information and details regarding the rationale for such change was lacking. Furthermore, specific and detailed information regarding the timing and duration of side effects and potential management options could also have aided couples:

*'I wanted more information for example the side effects of this is the same or more than Viagra? It doesn't affect your eyes. and I was going to make another appointment with that Dr who underwent this treatment but I am not sure to be honest.'*

M04

In addition to the pre-treatment stage, several couples noted that the consultations with the specialist following treatment were busy and hence delays were common in the out-patient department. Consequently, several couples felt pressurised to finish their appointment quickly and, in some cases, did not ask the specialist about all of their queries. The couples suggested that having an appropriate healthcare professional to contact by phone may be beneficial when additional information was required:

*'But the problem with this is that when you have questions and you know that there are a lot of people waiting outside and that have been waiting for a long time you will not ask all the questions as you don't want to take too long. That is why I am telling you that there needs to be some more support I mean at least let say for the prostate they give you some telephone number and that person may guide you accordingly you know.'*

## Findings

F12

Most couples relied on their immediate family (for example children) for support. However, if this support was not available it may result in unmet supportive care needs for the couple. One particular couple (couple 13) appeared to be struggling with their emotional wellbeing following treatment for prostate cancer. The man experienced more severe urinary side effects and also required a catheter during and immediately after treatment, therefore requiring additional support and assistance. The support and assistance were provided by the spouses, however the spouse indicated that this was particularly emotionally challenging and a lack of support from their children made it even more difficult to cope with the changes caused by prostate cancer:

*'You know I think what we didn't have was our children's support as they don't live over here, you know they live in UK. So, we didn't have any support from them I mean my brothers and sisters they don't come over here you know they have their own families.'*

F13

*'How were you dealing with the situation?'*

GvD

*'It is not the physical aspect or for example changing the nappies or the catheter it is more the psychological aspect, the support you know. That you have someone who will be checking on you how everything is going you know.'*

F13

## **5.7. CONCLUSION**

This chapter presented a detailed account of men and their partners within the first two years of completing external beam radiotherapy treatment. This chapter suggests that men may experience a range of physical, psychosocial and sexual consequences that not only affect them but also have a considerable impact on their spouses and, collectively, their relationships. Whereas some men appeared to adopt a more individual approach to dealing with prostate cancer, and therefore often did not directly involve their spouse in the process, others adopted a more dyadic approach to dealing with their condition.

Spouses often had an important role in the provision of emotional support for their husband. However, providing such support and dealing with the impact of a prostate cancer was often emotionally challenging for some women.

The communication process adopted by the men and/or their partners may subsequently have an important function in their adjustment to prostate cancer. Findings suggested that most couples appeared to avoid open cancer-related discussions. The couples suggested several areas where their experience could have been improved, these included the provision of relevant information prior to the commencement of treatment and greater clinical support following the completion of treatment.

This chapter provided an overview of key findings, the following chapter critically discusses these in more detail.

## CHAPTER 6. DISCUSSION

### 6.1. INTRODUCTION

The aim of this study was to explore the experiences of men (aged 64-74 years) and their partners in the first two years following external beam radiotherapy treatment for prostate cancer in Malta. The specific objectives of this study were to explore:

- Experiences of the healthcare system for men and their spouses before commencing external beam radiotherapy treatment.
- Experiences of undergoing external beam radiotherapy treatment for prostate cancer for men and their spouses.
- Men and their spouses' experiences of the follow-up care after the completion of external beam radiotherapy treatment for prostate cancer.
- The impact of an external beam radiotherapy treatment for prostate cancer on the life and relationship of men and their spouses.

This chapter discusses the findings presented in Chapter 5 and focuses on three main aspects.

The first part will focus on the emotional impact on couples of a prostate cancer diagnosis, and treatment. In particular, the experience of prostate cancer treatment is associated with a range of stressors, these can occur prior to treatment (for example lack of information and uncertainty), during treatment (for example bladder filling during radiotherapy) and after completion of treatment (for example dealing with lack in stamina and sexual changes due to prostate cancer treatment). Although these stressors varied between the different treatment periods, they all had an impact on the emotional well-being



## Discussion

of men and their spouses and therefore will be further discussed in this chapter.

The second part of the chapter will focus on the impact of a prostate cancer treatment on the lives and relationships of couples. Findings suggested that some couples were able to maintain or redefine their relationship following treatment and, in some cases, even commented that the experience had brought them closer together as a couple. Such couples adopted a shared approach in dealing with the consequences of prostate cancer. Conversely, other couples appeared to adopt a more individual approach to dealing with the illness. It is proposed that these different approaches may be related to the different communication patterns used by couples and may also be influenced by gender and sociocultural norms present in the local setting.

In the third part of the chapter it is proposed that couples' coping and adjustment had a strong link to models related to stress and coping, notably the Development Contextual Model (DCM) of dyadic coping (Berg and Upchurch 2007). Therefore, in the last section, I propose how this model can better inform the process of couples' adaptation to prostate cancer and the implications for healthcare professionals.

Although the study focussed on couples following prostate cancer treatment, it should be acknowledged that this study only recruited couples who were in long-lasting heterosexual relationships. According to Kelly et al. (2017), heteronormativity may have a pertinent role in shaping service provision. Heteronormativity has been defined as the 'hegemonic discursive and nondiscursive normative idealisation of heterosexual' (Hird 2004, p27). Service provision may mirror heteronormative assumptions by failing to challenge assumptions about information needs related to prostate cancer. The experiences and needs of other couples or pairs other than heteronormative pairs may vary from this study. For example, the

## Discussion

experiences and needs of homosexual couples or couples in short term relationships may vary from this study. In addition, couples or pairs may also consist of platonic close relationship such as siblings and their experiences and needs may also vary.

### **6.2. EMOTIONAL IMPACT OF A PROSTATE CANCER DIAGNOSIS AND TREATMENT ON COUPLES**

The diagnosis and treatment of prostate cancer can impact upon the emotional wellbeing of men and their spouses. Study findings indicated that one of the greatest consequences of a prostate cancer diagnosis and treatment is the emotional impact on couples.

The physical symptoms of a prostate cancer diagnosis and treatment (for example urge incontinence, erectile dysfunction and fatigue) can have a negative impact on emotional wellbeing and are a significant source of distress (Berg et al. 2008). It has been reported that at any given time, 20-60% of patients with prostate cancer may suffer from anxiety in general (Watts et al. 2014; James et al. 2022). Anxiety, or stress, is seen in various forms in prostate cancer patients and their partners and may occur at any point during the prostate cancer journey (Watts et al. 2014; Chien et al. 2019). In addition, men undergoing prostate cancer treatment may experience a range of treatment-related side effects, which can also affect their emotional wellbeing. Common side effects include fatigue, urinary (for example urgency, hesitancy) and bowel problems (for example diarrhoea) (Resnick et al. 2013) due to radiotherapy treatment and hot flushes and weight gain, as a result of hormone treatment (Elliott (nee Murray) et al. 2015; Nguyen et al. 2018). My study suggested several specific areas that may be considered as a source of anxiety and distress for couples throughout their prostate cancer journey. These included pre-treatment communications with healthcare professionals, bladder filling procedures during radiotherapy treatment and post-treatment follow-up care, these are discussed in more detail below.

## Discussion

### 6.2.1. Pre-treatment communications with healthcare professionals

A common source of anxiety and concern for couples was the perceived delay and long waiting time before the prostate cancer diagnoses and treatment. Within the literature, anxiety levels have been reported to be highest in those awaiting biopsy results and primarily appear to be related to the potential biopsy outcome (Sousa et al. 2012; Watts et al. 2014; Sefik et al. 2020). Findings from my study indicated that the initial period, from elevated PSA levels until the commencement of treatment, was particularly stressful due to participants' perceptions that healthcare professionals often did not appear to appreciate their concerns regarding the urgency of a potential prostate cancer diagnosis.

Couples felt that the precise reason for long waiting times and/or delays was largely unclear, and the lack of a definitive diagnosis was therefore a significant source of distress. These concerns suggested a deficiency in the provision of appropriate information from health professionals, regarding clinical timeframes for the diagnosis and subsequent treatment for prostate cancer, for the participants. Couples were often not prepared to wait several months to get a biopsy in the local general hospital and felt that healthcare professionals did not treat their case with the urgency that they deemed necessary. A general feeling expressed by the couples was that health professionals often highlighted the relatively slow-growing natural course of prostate cancer, possibly to reassure them about the related clinical timeframes. However, by highlighting the slow-growing nature, couples perceived that healthcare professionals were in fact justifying the excessive waiting times for investigations and treatment, rather than acknowledging their concerns. Couples were concerned and worried that any delay may have a negative impact on the outcome of treatment and there was a lack of explanation from healthcare professionals regarding the need or reason for such delays.

## Discussion

Delays in diagnosis and treatment may negatively impact the outcome of treatment for men diagnosed with prostate cancer. Although several studies, discussed further below, investigated the impact of treatment delay on the outcome following treatment, these studies appeared to mainly focus on the clinical outcome. Findings from this study indicated that delays were associated with significant anxiety and distress for men and their spouses, although emotional outcomes are not routinely included when evaluating the impact of a delay on prostate cancer patients. For example, Awasthi et al. (2019) investigated the effects of a delay from prostate biopsy to surgery on outcomes for men with localised disease in the USA. This multi-institutional cohort study included 1807 patients who received prostatectomy between 1987 and 2015. The authors suggested that a gap of 120 days from the day of diagnosis until treatment was not associated with adverse pathological or oncological findings at surgery for low-risk groups (Awasthi et al. 2019). Similarly, van den Bergh et al. (2013) performed a systematic review, they summarised the current literature on the impact of treatment delay on prostate cancer oncological outcome. Van den Bergh et al. (2013) suggested that a delay in diagnoses and/or treatment of several months or even years appeared to have no impact on the outcome for low-risk prostate cancer. However, van den Bergh et al. (2013) noted that for intermediate and high-risk diseases, the risk of missing the curability window is a realistic concern and they considered a three month timeframe to be an acceptable period in which additional diagnostic investigations and treatment choices could be made (van den Bergh et al. 2013). Although van den Bergh et al. (2013) suggested that a treatment delay could also negatively impact the emotional wellbeing, the negative effect on the physical and psychological outcomes were unknown (van den Bergh et al. 2013).

A more recent systematic review and meta-analysis by Chan et al. (2021) evaluated the evidence surrounding the delays for patients with

## Discussion

different risks of prostate cancer (for example low-risk, intermediate-risk and high-risk) to inform and prioritise prostate cancer treatment (Chan et al. 2021). Chan et al. (2021) reported that evidence is uncertain in postponing surgery, but that conservative estimates suggest that delays of five months, four months, or 30 days for respective low-, intermediate-, or high-risk patients, respectively may lead to worse survival outcomes. While Chan et al. (2021) specifically included men who underwent prostatic surgery, it is unclear whether these results are comparable for men undergoing other forms of treatment such as external beam radiotherapy. In addition, the outcomes in Chan et al. (2021) were measured in clinical outcomes (for example cancer specific survival and biochemical progression-free survival) and did not assess the impact of such delays on the emotional wellbeing of patients and their spouses. The above studies may therefore suggest that the risk of missing the curability window is a realistic concern, which might help explain why participants in my study were so concerned about delays to diagnoses. However, it should be noted that the risk classification is not known during the initial consultations with healthcare professionals, further examination is required. Also, couples who voiced their concerns about delays felt that these were not adequately addressed by the health professional, this further compounded their anxiety.

For men, prostate cancer is a potentially life-threatening illness associated with significant distress, this may also influence spouses. Therefore, it is not unreasonable to expect expediency regarding assessment, diagnoses, and the initiation of an appropriate treatment. However, these understandable concerns do not seem to be adequately addressed during specialist consultation and appear to further compound participants' anxiety regarding the potentially progressive development of cancer, despite reassurances to the contrary.

## Discussion

This study revealed that the pre-treatment information needs for couples diagnosed with prostate cancer varied considerably. Some couples wanted to receive little information about the diagnosis and treatment, whilst others wanted to be fully informed and involved in the treatment decision making process. Similar results have been noted in the wider literature which suggests that prostate cancer patients' information needs to vary considerably (Feldman-Stewart et al. 2010; Kassianos et al. 2016), this highlights the necessity for a more person-centred approach in the pre-treatment discussion process with healthcare professionals. A person-centred communication approach, which takes individual information preferences into account, is positively associated with QoL in prostate cancer patients (Paterson et al. 2013; Velikova et al. 2018; Penedo et al. 2020). In particular, when experiences with health professionals were less positive, this was often due to a failure to recognise patients' and partners' information and supportive care needs (Johnson et al. 2021; Sinfield et al. 2008). Findings from this study revealed that healthcare professionals often failed to address the concerns that participants had in relation to their prostate cancer diagnosis. Concerns varied between the couples, some expressed concerns about a rapid increase in PSA value or diagnosis with a high Gleason grading. These concerns were often not addressed adequately from the couples' perspective and this remained a source of concern.

The literature suggests that some men and their spouses may experience insufficient information, or an overload of information and related communication problems with healthcare professionals, in relation to prostate cancer (Paterson et al. 2015; Kirkman et al. 2017; Bamidele et al. 2019). However, findings from my study suggested that it is not necessarily the amount of information provided, as such, but rather that the focus of information related discussion led by health professionals was primarily on disease and treatment options. Furthermore, findings from this study indicated that, where

## Discussion

appropriate, couples needed information that was more tailored to their personal circumstances, and which was provided at the right time. For example, some couples indicated that they received most of the information regarding potential treatment options for prostate cancer during the time of their prostate cancer diagnosis. As these couples had only just been made aware of their prostate cancer diagnosis, they may be less prepared to process all this information.

Chen et al. (2021) explored the specific information needs of men and their partners affected by prostate cancer. This qualitative descriptive UK study included 19 men and 6 partners who were at different cancer stages, semi-structured interviews were conducted over the phone. Chen et al. (2021) also noted gaps in information provision, specifically that most information was provided during the initial diagnosis phase, prior to prostate cancer treatment. The information often featured textbook answers and population-level statistics but was not sufficiently customised to participants' individual information needs. While the participants in this study also expressed a desire for the provision of information to be tailored to their individual needs, most participants in the study by Chen et al. (2021) were members of a prostate cancer support group, this could have resulted in participants being better able to self-advocate and more inclined to seek relevant support. Some participants in the study by Chen et al. (2021) suggested that patients themselves needed to be more proactive in soliciting information from health professionals. However, my findings indicated that most men do not take a proactive approach to information seeking and often did not ask for further information about different treatment options or potential treatment related side effects. Consequently, this passive approach may lead to misconceptions regarding the duration and severity of potential side effects. Different understanding between men and their spouses can lead to relationship tension and this may therefore negatively impact the couple's emotional wellbeing. The provision of more detailed

## Discussion

information which is tailored to the needs of men and their spouses should therefore be a priority of healthcare professionals. Although some men and their spouses may adopt a passive approach to information seeking, efforts should be made by healthcare professionals, where possible, to better involve them in prostate cancer care from an early phase (for example diagnosis and treatment decisions).

Involving patients and their spouses in management decisions might have reduced some of the misconceptions about the timing and severity of side effects identified in this study. The wider literature indicates that involving patients and close family members in the treatment-decision making process has several advantages, these include reporting higher levels of satisfaction with care, increased knowledge about their condition and more realistic expectations about benefit and harm of a treatment (Stacey et al. 2014; Krist et al. 2017; Martínez-González et al. 2019).

The patient-physician relationship represents an essential factor in treatment decision-making (Orom et al. 2016). Patient decision-making regarding treatment options is often associated with anxiety (Skyring et al. 2021), this is due to a variety of management options which are highly dependent on men's individual preferences and lifestyles (Violette et al. 2015). Treatment decisions for prostate cancer commonly occur within patients' social networks, with partners often facilitating men's choice of treatment (Emslie et al. 2009).

Shared decision-making is promoted in many western health systems in countries, such as the UK (Carmona et al. 2021), the Netherlands (van der Weijden et al. 2022) and at European Union level (Lawler et al. 2021). Also in the Maltese setting, a fundamental guiding principle is the participation of the patient in their care process by using shared-decision making when possible (Ministry for Health [Malta] 2017). However, findings from my study suggest that although men's



## Discussion

involvement (in particular) in the treatment decision-making process varied. Two main different decision-making styles were identified. While some men preferred to be closely involved in the treatment decision making process, others largely left it to their physician. Similar findings are noted in the literature, which perhaps suggests that some men prefer their physicians to decide on their behalf (Cuypers et al. 2016) especially if they are older (van Weert et al. 2016). However, this study did not identify differences between the age groups, although the men's average age was relatively similar. A local study by Azzopardi et al. (2017) assessed patients' preferences for receiving a cancer diagnosis and being involved in the decision-making process, this also indicated that patients still exhibit a paternalistic attitude towards their physician.

Although Azzopardi et al. (2017) noted a trend towards a collaborative and active role in the decision-making process, the majority 68.2% (n= 134) of participants experienced a passive role in the treatment decision making process. Such findings may indicate that in the local setting, most patients and spouses may prefer to be minimally involved in this process. However, such an approach may lead to misconceptions regarding the outcome of treatment, in particular the timing and severity of side effects as indicated in my study. Although the study by Azzopardi et al. (2017) was conducted in the local setting, this study includes all cancer types and only a small subsection of 9.2% (n=19) were prostate cancer cases. Therefore this may have influenced the results of the research. However, there is some evidence to indicate that men may rely more on their physician to make a treatment decision (Cuypers et al. 2016; van Weert et al. 2016).

The wider literature suggests that men diagnosed with prostate cancer who have a more active role in the decision-making process are usually more satisfied with the treatment chosen (Skyring et al. 2021), presumably because there is a sense of ownership. However, while

## Discussion

my study did not specifically investigate the treatment-decision making process, findings indicated that couples who were more closely involved in the decision-making process appeared to have a better understanding of common treatment related side effects. Furthermore, when both men and their spouses were involved in the treatment-decision making process they tended to collaborate more closely with each other when compared to men who left the treatment-decision to the physician.

Consequently, shared decision making may not only be beneficial for their understanding of treatment side effects and satisfaction with care, as outlined previously, but it may also be beneficial for their marital relationship. In particular, it may facilitate their cancer-related communication process. In addition, couples that tend to collaborate more closely about treatment-decision making, appear to maintain a more open style of cancer-related communication after the completion of treatment.

Physicians therefore have a responsibility to involve patients and their spouses in the treatment decision-making process, where possible, and ensure that they are well informed about the need for treatment, the risks associated with such treatment, the possible outcome benefits (for example prolonged survival) (Becerra Pérez et al. 2016) and side effects, including the duration of side effects. However, findings of my study revealed that information regarding potential treatment regimens was not always correct. It appeared from my findings that some couples made their treatment-decision without having all the information available. In fact, following additional examination (for example, Magnetic Resonance Imaging (MRI) scan), several men were advised to change their preferred treatment choice, the reasons for which were not properly explained, which resulted in distress.

## Discussion

Couët et al. (2015) undertook a systematic review to explore the extent to which healthcare professionals involve patients in generic treatment decision-making processes. They included studies that adopted the Observing Patient Involvement in Decision-Making instrument (OPTION) to observe the extent to which healthcare providers involve patients across a range of clinical contexts (Couët et al. 2015). Few healthcare professionals consistently include patients in treatment decisions and even fewer adjust care, where appropriate, to align with patient preferences (Couët et al. 2015). However, this review included a range of health conditions besides cancer, for example depression, diabetes and heart disease and therefore the transferability of findings to prostate cancer patients is unclear. In addition, the studies included in this review were mainly conducted in the USA, UK or Germany and therefore the health care setting and social cultural backgrounds may be different to Malta.

Two studies which specifically investigated patient-physician communication in prostate cancer also identified that clinicians infrequently offered patients choices regarding their treatment options or explored patient views and preferences (Pieterse et al. 2011; Holmes-Rovner et al. 2015). However, these studies analysed audio-recorded consultations only and did not include participants' views or preferences, thus it is unclear how patients perceived such encounters.

Renzi et al. (2017) performed a qualitative study exploring patient empowerment in prostate cancer. This study adopted in-depth semi-structured interviews to assess the experiences of prostate cancer patients during radiotherapy treatment to provide insights for clinical practice, with a particular focus on the design of a web platform to promote patient empowerment. Ten men were included in this study and all men underwent radiation therapy in a hospital in Milan, Italy. Renzi et al. (2017) identified that most of the communication from

## Discussion

healthcare professionals was directive and information provision, this primarily involved the clinician explaining treatment options that he deemed appropriate. However, such a communication style can be perceived as a sign of detachment from clinicians and may therefore be detrimental to the therapeutic relationship between the patient and the healthcare professional (Renzi et al. 2017). Such a communication style may lead to the patient being less involved in the process and could result in misunderstandings about treatment efficacy and longer-term side effects. It should be noted that the study by Renzi et al. (2017) was undertaken in Italy and that the communication styles of physicians in Italy may differ when compared to the local setting.

In this study, the role of men and their spouses in the treatment decision-making process was identified as predominantly passive (when the physician essentially decided on their behalf) and some couples were actively involved (when the physician left them to decide). This suggests that the caring model is still perceived as either placing the treatment-decision responsibility on the physician or putting it on the patient and family. However, my study did not indicate that a shared treatment-decision making process was used, although shared-decision making is often viewed as a key component of patient-centred care (Stiggelbout et al. 2012; Covvey et al. 2019; Josfeld et al. 2021).

Shared-decision making is a process whereby patients and healthcare professionals actively select the treatment options that best fit the individual's needs and preferences (Stiggelbout et al. 2015). Whilst many men preferred to leave the treatment decision to their physician, research suggests that the use of shared-decision making leads to lower decisional conflict and potential regret over the decision made (Marshall et al. 2005; van Stam et al. 2018).

Greater patient involvement may result in better psychological adjustment and satisfaction (van Stam et al. 2018). Several men and

## Discussion

their spouses in my study noted that they were not adequately prepared for treatment-related complications, particularly in the longer term, this suggests that there is room for improvement in the provision of appropriate information and greater patient involvement in treatment decision making. Healthcare professionals should therefore encourage patients and their spouses to be more actively involved in the treatment decision-making process, where possible, with the aim of improving their knowledge of and satisfaction with treatment (Martínez-González et al. 2019).

Patient-centred care is an essential target of quality care for cancer patients (McCorkle et al. 2011). For prostate cancer, the involvement of patients and their spouses in treatment-related decisions is critical, particularly because of the associated side effects they face in the daily management of the disease. In addition, side effects from prostate cancer treatment often occur following completion of treatment when support from healthcare professionals is often limited.

### 6.2.2. Bladder filling during radiotherapy treatment

A notable source of anxiety and distress for men during their radiotherapy treatment was the bladder preparation procedure. Men were required to follow a standardised treatment preparation procedure, whereby they had to maintain a full bladder for the duration of each daily radiotherapy treatment. A lack of compliance with prostate cancer treatment preparation can lead to treatment delays for patients and increase workload for staff (Horton 2020). Maintaining a full bladder can be challenging for men with prostate cancer, most men in the current study were worried that they would not be able to maintain a full bladder and that this could lead to urinary leakage whilst undergoing external beam radiotherapy treatment. Indeed, my study revealed that two men experienced urine leakage on the machine which brought about significant feelings of shame and embarrassment. Furthermore, another concern was that they would

## Discussion

lose their allocated time slot and would have to start their treatment preparation from the beginning, which commonly takes around an hour.

The existing literature provides limited evidence regarding patients' perceptions of bladder preparation. Smith et al. (2022) performed a cohort study to determine whether patients had a sufficiently full bladder at the time of treatment delivery whilst being able to hold their bladder for the duration of treatment. The first ten patients were recruited as part of the implementation of a new treatment protocol using a Magnetic Resonance (MR) linear accelerator for prostate cancer treatment in the UK (Dunlop et al. 2020). The patients were asked to empty their bladders and to drink 350ml of water with a 45-minute wait for the planning Computer Tomography. This was followed by a 30-minute wait for treatment in order to achieve a bladder volume of 200-300cm<sup>3</sup>. In addition, variations to volume of water and wait time were permissible to meet optimal bladder volume (for example between 200-300cm<sup>3</sup>) and provide patient comfort. To establish adherence to bladder filling protocol, volumes of water drank, and the wait time were recorded daily on the patient data management system. In addition, patients were asked about the impact of bladder filling on their general experience of radiotherapy treatment, and whether a full bladder affected them before and during the treatment. Volume of water and wait times were recorded for 192 sessions and the bladder protocol was followed on 91 occasions, with the remaining 101 volumes of water and/or wait time altered to meet optimal bladder volume or provide patient comfort. There were six occasions (around 3%) when the patient could not hold their bladder for the duration of treatment. Only two patients provided feedback on their experience, and they noted that it was challenging to maintain a full bladder during treatment, one had difficulty following the protocol which caused some anxiety. Both patients indicated that not filling their bladder would have been a more positive experience and that it would have made the

## Discussion

treatment more comfortable and less stressful (Smith et al. 2022). When reviewing the results of Smith et al. (2022), it appears that the water intake varies, when compared with the local Maltese setting. The current bladder filling protocol in the local hospital stipulates that patients must drink four cups of water (approximately 800ml in total) and wait for 30 minutes; this appears to be a greater quantity of water compared with the study by Smith et al. (2022). However, it should be noted that Smith et al. (2022) reported that in more than half of the occasions there was a deviation from the protocol, this may have affected their results. Furthermore, the Smith et al. (2022) study included a relatively small sample size, with only ten participants included, only two participant provided feedback regarding their experiences of bladder filling. In addition, the treatment with MR linear accelerator using an adaptive radiotherapy technique may have increased the treatment time when compared with treatment on a linear accelerator currently available in the local setting.

Another study that took participants' feedback into account was a study performed by Mullaney et al. (2014). Mullaney et al. (2014) compared two different bladder filling protocols (540ml and 1080ml water consumed respectively and wait 30-40 minutes prior to treatment) to determine which bladder filling protocol achieved a consistent bladder volume. Secondary endpoints were used to assess the incidence of acute and late GU and GI toxicities and patients' satisfaction with the bladder filling protocol. This single institutional study included 110 participants who were randomly assigned to one of the two different bladder filling protocol arms. Mullaney et al. (2014) indicated that there was significantly less bladder volume variation in the 540ml arm when compared with the 1080ml arm during the radiotherapy ( $p < 0.0005$ ). In addition, no statistically significant association was identified in the side effects (for example GU and GI) and patients' satisfaction scores when comparing the different bladder filling protocols. Although Mullaney et al. (2014) did not find differences

## Discussion

in patients' satisfaction scores when comparing both treatment arms, findings indicated that when larger amounts of water were consumed this was more difficult to reproduce. A limitation of the study by Mullaney et al. (2014) is that following the consumption of water, patients had to wait between 30 and 40 minutes which could have consequently resulted in variations in bladder volume during this time period.

There is a lack of consensus about bladder filling protocols, they vary between centres all over the world, particularly in relation to the amount of water and the requisite wait times that are required for treatment to ensure an acceptable bladder volume. For example, Hynds et al. (2011) asked patients to empty their bladder and drink 500ml of water, treatment commenced thirty minutes later. Others, such as Braide et al. (2019), asked patients to drink 300ml of water and proceed with treatment one hour later. A systematic review and meta-analysis by Chen et al. (2020) investigated bladder volume reproducibility, they also identified significant variation between the amount of water consumed and the wait time for treatment. Chen et al. (2020) noted that the bladder volume of patients who consumed 300-400ml of water exhibited minimal differences between treatment and CT simulation, this is desirable to precisely deliver the radiotherapy treatment dose. These volumes suggest that the amount consumed in the local setting (800ml approximately) appears to be much greater, which may indicate the difficulties these men experienced during their treatment. Besides difficulties to maintain bladder volume during radiotherapy treatment, there is some evidence to suggest that a larger amount of water is more difficult to reproduce (Mullaney et al. 2014). As bladder filling protocols rely on the patient following the preparation procedure, a better understanding from the patient perspective is important. My study revealed that two men experienced urinary leakage, and most were concerned, particularly before and during the preparation process, that they would not be able



## Discussion

to maintain a full bladder while undergoing radiotherapy treatment. These concerns were a significant source of anxiety and distress and negatively affected their experience of undergoing radiotherapy treatment.

Studies have shown that variations in bladder filling affect the dose received by the prostate (Grün et al. 2019; Ingrosso et al. 2019; Roch et al. 2019), therefore bladder volume consistency during radiotherapy treatment is required. Maintaining a consistent bladder relies on a patient following the correct treatment preparation instructions. Many studies have found that bladder volume during radiotherapy treatment is less than during the CT simulation (Stam et al. 2006; Hynds et al. 2011; Braide et al. 2019; Chen et al. 2020). Although the reason for a reduction in bladder volume is often not clear, it is possible that patients' concern with potential urinary leakage can result in men reducing their water intake, this can lead to lower bladder volumes during treatment. In addition, larger bladder volumes can be more challenging to maintain during treatment and reproduce during treatment. An additional issue for these men is that common symptoms from prostate cancer include urinary complications (Merriel et al. 2018). Bladder complications are a common symptom of prostate cancer, and the illness is often diagnosed and treated in an elderly population who commonly report urinary complications. In addition to these factors, the use of external beam radiotherapy can result in further bladder complications (for example urgency and incontinence) (Nakamura et al. 2019), making it even more difficult to maintain a full bladder during radiotherapy treatment.

Although historically, the treatment of prostate cancer has been given with a 'full' or 'comfortably full' bladder, more recently, several institutions have been investigating the treatment with an empty bladder. Two studies (Morrison et al. 2019; Chetiyawardana et al. 2020) compared the standard bladder filling protocol with treatment

## Discussion

when the bladder was empty. Both studies indicated that the empty bladder protocol had no significant differences on acute toxicities when compared with the standard full bladder approach. Some limitations noted in these studies included the relatively small number of participants (50 and 90 participants respectively), and that the follow-up period varied (six weeks and 48 months respectively). In addition, patients' feedback with these different protocols was not considered.

As can be seen from the above studies, bladder filling for patients undergoing external beam radiotherapy treatment has been investigated widely regarding variations and the impact of such variation on the dose received. However, there appears to be a lack of detail and understanding from the patient's perspective. Patients' compliance with treatment preparation is essential to ensure a reproducible bladder volume suitable for treatment. This current study provides additional information from a patient's perspective which appears to be lacking in the related literature. Maintaining a reproducible bladder volume, which is comfortable for patients to sustain whilst achieving acceptable dose constraints, is an area that requires further attention. As bladder filling protocols rely on patients' ability to comply and drink the correct amount of water during a stipulated amount of time, their compliance and perspectives are essential to consider.

### 6.2.3. Post-treatment impact of prostate cancer treatment on couples

The impact of cancer and its treatment can lead to long-term health issues and can be detrimental to the QoL of patients and their partners (Eisemann et al. 2014; Adam et al. 2018). Findings revealed that men may suffer from a range of treatment related consequences such as urinary side effects (for example urgency, hesitancy and nocturia), sexual side effects (for example loss of libido and erectile dysfunction) and other physical side effects (for example fatigue and loss of

## Discussion

strength) which may negatively impact on their wellbeing and their QoL. Although the potential side effects from prostate cancer treatment have been extensively reported in the literature, less information is available about the way in which men and their spouses deal with such consequences, individually and/or collectively, and the subsequent support they therefore require from healthcare professionals.

The post-treatment effects of cancer require ongoing monitoring and coordinated follow-up care to ensure the management of persistent problems and early detection of emerging issues and late or long-term effects. However, findings from this study revealed that follow-up care, following the completion of prostate cancer treatment, did not always meet participants' expectations. Findings revealed three particular areas which may require further attention, and these include the social and emotional wellbeing, sexual functioning and follow-up care arrangements and these are further discussed below.

### 6.2.3.1. Social and emotional well being

My study findings suggest that the greatest consequences of a prostate cancer treatment are the social and emotional consequences, these may include a reduction in social contact patterns and negative mood or depression. These consequences were in some cases the result of the treatment-related side effects from prostate cancer, such as urinary complications.

Findings of my study revealed that urinary side effects, in particular urgency, were commonly experienced by the men, this had a negative impact on their social and emotional wellbeing. In particular, men wanted to remain in close proximity to the toilet as when the urge came, they believed they would not be able to hold their urine and were concerned about incontinence. This resulted in some men avoiding going out of the house and this therefore subsequently affected their social functioning. Changes in social activities and

## Discussion

networks also affect their spouses who are often considered to be the primary provider of social support for men (Nelson et al. 2019). The wider literature also indicates that urinary side effects are often rated as the most concerning for most men who have undergone prostate cancer treatment (Lehto et al. 2017). The fear of urine leakage or smelling of urine can be particularly humiliating for many men (Sutton et al. 2021).

Consequently, some men appeared to modify their behaviour accordingly and purposely chose to stay at home and/or avoid social contact, this can lead to significant anxiety and even depression in men with prostate cancer (Wright et al. 2019) as well as further social isolation (Ettridge et al. 2018). Findings from my study revealed that spouses may play a crucial role in helping their husbands adjust to the social impact of prostate cancer treatment, in particular when the men wanted to stay at home to avoid social contact. Some spouses actively engaged their husband in activities and social events, thereby trying to prevent social isolation. Similar findings were reported by Nelson et al. (2019) who explored the kind of social support men and their partners received and provided in the first 12 months following a localised prostate cancer diagnosis. Nelson et al. (2019) adopted a qualitative longitudinal approach with couples at three different time points (four weeks after diagnosis, three- four months post-diagnosis and 12 months post-diagnosis). The study involved 18 couples and included both individual (n=11) and couples' (n=7) interviews. Nelson et al. (2019) reported that support networks became smaller as time progressed and that men's primary support structure was their wife. While providing support for their husband was important, some spouses in the study by Nelson et al. (2019) reported that being the primary source of emotional support to their partner was increasingly tiring and they expressed difficulties in obtaining emotional support for themselves. Similarly, the men expressed the need for access to one-to-one emotional support from healthcare professionals (Nelson et al.

## Discussion

2019). Many couples, noted in the study by Nelson et al. (2019), mentioned the usefulness of attending social support groups to connect and share experiences with peers. However, in the local Maltese setting no support groups had been established at the time of my study, this could perhaps have led to greater unmet supportive needs for these couples.

Another potential issue identified in my study was the lack of disclosure of the prostate cancer diagnosis to wider friends and relatives, this often made it more difficult for the men to engage in meaningful social activities and in some cases led to social isolation. Such a lack of wider disclosure often resulted in couples trying to deal with the consequences of prostate cancer treatment alone, which may be problematic when couples do not have sufficient resources (emotional and/or practical) to be able to deal with the situation. Although a preference to limit the prostate cancer disclosure has been reported in studies conducted on men with prostate cancer (Gray et al. 2000; Grunfeld et al. 2013), my study indicates that spouses also preferred a limited disclosure and one spouse was upset when the man disclosed his diagnosis openly to friends and relatives. The limited disclosure to wider friends and relatives may be prominent in the local cultural setting and this will be further discussed in Section 6.3.3.

A prostate cancer diagnosis and treatment may adversely affect the social functioning of men and their spouses. Although spouses are often the primary source of social support (Nelson et al. 2019), providing such support to their husband can be emotionally challenging and some spouses may therefore also require emotional support. Findings of my study suggest that, for spouses, the emotional impact of prostate cancer often became apparent after the completion of prostate cancer treatment, some spouses even mentioned that it resulted in a depressed mood. Whilst the wider literature also indicates

## Discussion

that spouses could be negatively affected emotionally due to a prostate cancer diagnosis and treatment (Midtgaard et al. 2021), my study indicates that for spouses the repercussions often become apparent after the completion of treatment when there is less available support from healthcare professionals. Such findings therefore highlight the importance of providing emotional and social support to women and men following the completion of prostate cancer treatment.

The impact of prostate cancer on the emotional wellbeing and social functioning of men and their spouses is therefore an important aspect for healthcare professionals to consider. However, findings of my study suggest that the emotional wellbeing and social impact of prostate cancer were often not addressed during routine follow-up care. When these concerns are not addressed in a timely manner by healthcare professionals, they may lead to further deterioration in the patient's emotional wellbeing. There is some evidence to suggest that increasing social support to a patient with cancer may have a positive impact on their emotional wellbeing (Vodermaier and Linden 2019). Therefore, healthcare professionals could assess whether men and/or spouses have a desire for additional social support following prostate cancer treatment and what type of social support they would prefer. As outlined by Korotkin et al. (2019), there may be differences in the type of social support a patient and/or his spouse may desire such as companionship, home care support or information support (Korotkin et al. 2019). Therefore, providing adequate social support to couples following cancer treatment is an important area for healthcare professionals to consider. Providing such support is necessary to maintain their QoL and can reduce mortality and morbidity (Williams et al. 2019).

Findings of this study indicate that several men valued the opportunity to listen to men who had previously undergone prostate cancer

## Discussion

treatment, prior to commencement of their own treatment. Similarly, McCaughan et al. (2015) found that participants valued the opportunity to talk to other couples affected by prostate cancer who were of a similar age and experience. The addition of a 'buddying system' which connects couples of similar ages and experiences together may be beneficial for the social and emotional wellbeing of men and their spouses following the completion of prostate cancer treatment.

Besides the social and emotional impact of a prostate cancer diagnosis and treatment, another area that may require further attention is the consequence of prostate cancer on sexual functioning. This is further discussed in the next section.

### 6.2.3.2. Sexual functioning

A commonly reported side effect from prostate cancer treatment is erectile dysfunction, this can have a negative impact on a man's self-image (Chambers et al. 2017; Bowie et al. 2021) and may negatively impact couples' sexual intimacy (Wittmann et al. 2015). Findings from this study revealed that post-treatment sexual changes may be more profound for men who also underwent hormone treatment. Hormonal treatment is associated with a range of side effects including: hot flushes, weight gain and a loss of libido (Walker and Robinson 2010). As these side effects often became more apparent after the completion of treatment, several couples subsequently discussed their sexual issues with the healthcare professionals. To address treatment-related erectile dysfunction most men were offered erectile restoring medication PDE-5 inhibitors (for example Viagra). These men started the treatment in order for them to have 'natural sex'. However, all men discontinued their use as they had to plan sexual activity which felt 'unnatural'. These sexual changes had a negative impact on their mood and body image, this is further discussed in Section 6.3.2.1.

## Discussion

Spouses appeared to be less concerned, some even commented that the changes in their sexual relationship affected them less. However, some couples were dissatisfied with the level of information provided, and the lack of discussion about sexual consequences, by health professionals. Similar findings have been reported in the UK by Kelly et al. (2015) who investigated couples' perspectives about the impact of prostate cancer treatment on sexual intimacy. This qualitative study included 18 participants from a variety of backgrounds and maximum variation sample was adopted to encourage a heterogeneous demographic group. Kelly et al. (2015) indicated that discussing post-treatment sexual functioning with clinicians was challenging for couples as they had limited opportunities to discuss their psychosexual needs (Kelly et al. 2015). However, in my study, unlike the study by Kelly et al. (2015), it appears that some spouses were less concerned with the sexual changes caused by prostate cancer. These differences may be related to the age of the participants, as participants in the Kelly et al. (2015) study were between 34 and 78 years of age, it therefore included younger couples who may have higher sexual needs when compared with older couples following prostate cancer treatment.

Similar to the study by Kelly et al. (2015), couples in this study also noted that health professionals did not routinely discuss the impact of prostate cancer treatment on their sexual functioning and consequently they commonly had to raise these concerns themselves. If such discussion with health professionals is limited, it is likely to result in couples having unmet sexual health needs. Unmet sexual needs may lead to problems in relationship quality and satisfaction for both patients and their spouses (Ramsey et al. 2013). Therefore, healthcare professionals should better assess couples' sexual needs and, where appropriate, provide more relevant support to those required.



## Discussion

### 6.2.3.3. Follow-up care arrangements

Findings indicated that for some couples the current follow-up care arrangements did not always meet their expectations and this adversely affected their emotional wellbeing. Several couples in my study commented that follow-up consultations were often very busy, with many patients and relatives waiting some time for their appointment. Consequently, due to the dynamic nature of follow-up clinics, some couples felt pressurised to finish their appointment quickly so that others would not have to wait too long to be seen. This could, therefore, result in some couples having unmet supportive care needs which may negatively impact their adjustment to prostate cancer. In addition, several spouses felt that their concerns, such as the emotional impact of their partner's illness, were not addressed during follow-up consultations. Couples also noted a lack of information tailored to their specific needs, for example how the treatment and/or side effects may influence other medical conditions.

A common approach to cancer follow-up care is routine clinic appointments for all patients at pre-specified intervals, which is also the standard in the local setting. However routine clinical appointments do not always address specific needs (for example informational, emotional and practical) (Alfano et al. 2019). Frankland et al. (2019) investigated the implementation of a service improvement initiative for the follow-up care of prostate cancer patients, this was based on remote monitoring and supported self-management in four prostate cancer centres in England. A total of 627 men consented to take part in this study, 293 men followed the new programme, and 334 men were in the usual care group (Frankland et al. 2019). The primary outcome was men's unmet supportive care needs, as measured by the modified Cancer Survivor's Unmet Needs Survey (CaSUN) (Hodgkinson et al. 2007). To compare the prostate cancer health service, data were collected from both groups via the questionnaire at four- and eight-months' time period. Results of Frankland et al. (2019)

## Discussion

indicated that men who followed the new service implementation reported lower levels of unmet needs; in fact, 25 out of 26 items assessed in the CaSUN questionnaire were favouring the new programme, with four of these statistically significant. Frankland et al. (2019) suggested that remote surveillance or patient-led follow-up is at least comparable to appointment-based follow-up care in terms of patient reported outcome and is acceptable for men. However, some of the limitations of this study included the fact that men were not randomly assigned to each group, men were assessed by their clinical team as being suitable candidates for the new programme. This could have influenced the results as men were required to be functional and emotionally stable, therefore the new programme could have included more well-adjusted men with lower supportive care needs. In addition, spouses were not included in this programme, although spouses played an important role in the adjustment of their husbands. It is therefore not possible to assess how such follow-up programmes may influence their needs.

Identifying and addressing unmet needs of patients with cancer can prevent distress and improve QoL and satisfaction with care (Cochrane et al. 2022). Addressing unmet needs could allow couples to more effectively manage symptoms and treatment related side-effects and therefore enable them to better adapt to the consequences of prostate cancer treatment (Paterson et al. 2015).

### **6.3. A SHARED OR INDIVIDUAL APPROACH TO DEALING WITH PROSTATE CANCER**

This study revealed that some couples adopted a dyadic (that is shared) approach to coping with prostate cancer. However, other male participants perceived prostate cancer as more of an individual concern and, consequently, often did not meaningfully engage with their spouses in this process. The extent to which spouses are included in their partner's health concerns as part of their own future

## Discussion

goals may reflect 'illness ownership' (for example whether an illness is viewed as an individual concern or shared issue). Illness ownership or whether men and their spouses view prostate cancer as a 'shared concern' may have important implications for their coping efforts. Findings of this study suggest that couples who view the illness as a 'shared concern' more often adopted dyadic coping strategies (for example joint problem solving), whereas some men who viewed the illness as a personal issue often adopted more individual coping strategies (for example distancing or avoidance).

These different coping strategies appear to be closely linked to the use of different communication patterns, such as the use of relationship-enhancing communication (for example self-disclosure, mutual constructive communication) or relationship-compromising communication (for example holding back and mutual avoidance) (Manne and Badr 2008). In addition, gender and social cultural norms may also influence how couples react and cope with the changes caused by prostate cancer. These will be discussed in more detail, and I will consider how each aspect can inform individual or dyadic approaches to coping and adjustment, and the subsequent implications for spousal relationships and healthcare practice.

### 6.3.1. Cancer-related communication patterns

Findings from my study suggest that cancer-related communication patterns adopted by men and their spouses, appear to be closely linked to how couples appraised the illness ownership. Men and spouses who adopted a more individual approach to their coping and adjustment efforts, appeared to adopt more relationship-compromising behaviour (for example avoidance). Whereas couples who adopted a shared or dyadic approach, often used more relationship-enhancing communication patterns (for example mutual constructive communication).

## Discussion

Manne and Badr (2008) proposed that relationship communication can either enhance or compromise the marital relationship. Manne and Badr (2008) noted that couples may adopt relationship-compromising behaviour, such as holding back concerns and avoiding cancer-related discussions, this has also been found in my study. Avoidance and concealing cancer-related concerns have been indicated to predict poorer psychological outcomes for both men and their spouse following prostate cancer treatment (Manne et al. 2021). Manne et al. (2015) noted that 'holding back' was strongly associated with both partners' well-being and distress and was particularly detrimental for couples' intimacy and relationship satisfaction (Manne et al. 2015). Similarly, mutual avoidance strategies have been associated with lower marital satisfaction among men with prostate cancer and their spouses (Badr and Taylor 2009) and are directly associated with greater psychological distress (Manne et al. 2015).

Similar findings have been reported in the wider literature on men coping with prostate cancer. For example, Ettridge et al. (2018) noted that following prostate cancer treatment, men often hide their emotions from others, including their wives. Such an approach may be adopted by men to protect their wives from undue worry or concern (Chambers et al. 2018). In fact, some of the men in my study perceived that their spouses were not able to cope with the emotional impact of the illness and subsequently they tried to limit their involvement.

Avoidance is relatively common amongst men and is characterised by non-engagement with information seeking (Hanly et al. 2014) and/or minimising the impact of treatment side effects (Eziefula et al. 2013). However, individuals who adopt avoidance strategies often report more relationship problems, such an approach has been linked to poorer dyadic coping efforts (Kuster et al. 2017). Use of avoidance has been reported to have a negative impact on the QoL and mood of men and their partners (Nipp et al. 2016). Therefore, the use of these

## Discussion

individual coping strategies may be detrimental for the dyadic coping efforts and communication patterns and may be an important aspect for healthcare professionals to consider when evaluating the adjustment of couples following prostate cancer treatment.

Findings from my study revealed that many men tried to hide their emotions from their partners and did not involve them in attendance at radiotherapy treatment sessions. In addition, some spouses commented that they avoided cancer-related communication, both men and spouses raised the issue that they needed to remain 'strong' in front of their partner and others. Such views were more commonly expressed by the men and appeared to be closely linked to their perceived male gender perceptions, this is further discussed in Section 6.3.2. Remaining 'strong' in front of others, including their partner, was due to a desire to support their partner or spouse, this was represented to present oneself as capable of coping and being emotionally unaffected. However, such an approach may lead to more relationship-compromising behaviour such as holding back concerns and avoidance and could be detrimental for a shared or dyadic approach when dealing with the impact of prostate cancer.

Other couples in my study were more open about sharing their emotions and concerns with each other and often adopted more 'relationship-enhancing behaviour', as outlined by Manne and Badr (2008). According to these authors, relationship-enhancing behaviour includes greater cancer-related disclosure and mutually constructive communication, including discussing and expressing feelings about cancer-related concerns (Manne and Badr 2008). The use of relationship-enhancing behaviour, such as self-disclosure, has been linked with greater intimacy (Porter et al. 2005) and with lower psychological distress (Manne et al. 2006). Findings from my study suggest that when couples adopted such approaches, spouses were more involved in the prostate cancer process such as accompanying

## Discussion

their husbands to treatment sessions and being involved in the treatment decision-making process.

Although the wider literature suggests that open, meaningful cancer related discussions amongst couples is crucial to their adjustment to prostate cancer (Manne et al. 2021); difficulties in openly discussing their concerns with each other may have been present before the diagnosis of prostate cancer. Findings from this study revealed that it was the men who often initiated whether or not there was an open, meaningful discussion between themselves and their spouses. Some of the men perceived that the illness only directly affected them and therefore commonly believed that they were capable of dealing with the consequences on their own without the help of their partner. Some of these men even commented that they felt their partners were unable to cope with the disease as they were too worried or emotionally affected. By dealing with the illness independently, some men could also perhaps show their resilience and possibly align themselves more closely to their perceived masculine self-image.

Similar findings have been reported by Bamidele et al. (2019), who investigated the psychosocial consequences of prostate cancer amongst Black African and Black Caribbean men and their partners in Northern Ireland. Bamidele et al. (2019) identified that some men 'took personal control' of their disease and involved their wives minimally. Bamidele et al. (2019) suggested that there appeared to be a hierarchy of power between the men and their spouses in which the men were dominantly positioned as 'the leader' whilst their partners mainly operated from a supportive and 'accepting' position. Such an approach may be due to the cultural norm and background of Black African and Black Caribbean men and their partners. According to Bamidele et al. (2019), spouses often felt isolated and excluded from their husbands' cancer journey, especially regarding information, psychosexual support, and marital communication. Although such findings were not

## Discussion

specifically identified in my study, some men did try to take control of their disease and minimally involve their spouses. This may therefore suggest that relationship dynamics such as the use of different communication patterns, and issues such as power and control within a relationship, may have important implications on how couples cope and adjust following a prostate cancer treatment. While most men in the Bamidele et al. (2019) study articulated that sexual recovery was their primary need, most of the participants were younger (65 years or less), which may account for the importance of sexual needs. In addition, relationship dynamics may change when couples grow older, as older couples tend to rely more on each other to meet daily challenges and to remain independent (Harden et al. 2006). Older couples tend to collaborate more and communicate more with one another due to compensation of declined cognitive or physical abilities or because they spend more time together in retirement (Smith et al. 2009). In addition, relationship dynamics may be shaped according to the sociocultural background in which couples interact and therefore differences may exist in the local setting.

My study included men aged 64-74 years and their partners (mean age 64 years) and this age group has been suggested to be a transitional period where most adults enter retirement. Whereas most men in the study of Bamidele et al. (2019) did not involve their spouse in the recovery process following their prostate cancer treatment, several of the couples in my study did collaborate and communicate with each other in order to share their issues and concerns whilst dealing with the negative consequences of prostate cancer. The involvement of spouses in the prostate cancer pathway can have a positive impact on couples' psychological functioning and relationship satisfaction (Falconier et al. 2015). Findings of my study also suggest that some couples noted that the prostate cancer experience brought them closer together as a couple.

## Discussion

Cancer-related communication patterns appear to be closely linked to an individual or shared approach to dealing with prostate cancer. In addition, illness ownership, or whether individuals appraise the illness as a shared or individual concern, may be an important starting point for a more individual or shared approach in dealing with the consequences of prostate cancer and could have important implications for healthcare professionals. Healthcare professionals should acknowledge and assess the impact a prostate cancer diagnosis has on the spouses, which in turn may lead to a more shared approach. In addition, involving the spouse in the discussions regarding treatment options and outcome of treatment may also enhance a more shared illness appraisal. This may lead to greater collaboration between men and their spouses and could lead to more relationship-enhancing communication patterns.

Another factor that may influence how men and woman cope and adjust to prostate cancer is their perceived gender role, this appears to be closely aligned to cultural norms. This is further discussed in the next section.

### 6.3.2. Gender and role expectations when dealing with prostate cancer

Findings from my study suggest that men and their spouses may behave differently on a diagnosis and treatment for prostate cancer, and this may be closely linked to their gender. Although it should be noted that prostate cancer is a gender-specific illness, the behaviour adopted by men and their spouses in my study appears to be associated with traditional gender roles and characteristics (for example masculinity and femininity) and this is further discussed in the following subsections.



## Discussion

### 6.3.2.1. Men and prostate cancer

According to Wall and Kristjanson (2005), there may be a cultural or social expectation that men surviving prostate cancer will cope and adjust to the changes caused by the cancer. Several authors who investigated men undergoing prostate cancer treatment identified this approach and termed it 'withdrawing into themselves' (Appleton et al. 2015) 'emotional distancing' (Levy and Cartwright 2015) or 'going it alone' (Kazer et al. 2011). Similar approaches have been identified in this study, they were termed 'dealing with prostate cancer alone' (See Section 5.4.2.), and such approaches appear to have a strong link with men's masculine identity.

Masculine identity is socially constructed in interactions with others, and it is constantly being tested and renegotiated within each context (Araújo and Zago 2019). Diminished masculinity due to post-treatment sexual dysfunction has been previously reported in the prostate cancer literature (Wittmann et al. 2014; McCaughan et al. 2015). Findings from my study also revealed that the side effects from prostate cancer treatment can cause sexual (for example erectile dysfunction and loss of libido) and physical (for example increase in weight and loss of strength) changes which can have a negative impact on a man's self-image. Therefore, the physical side effects associated with prostate cancer may influence the emotional wellbeing of men. In addition, masculine identity may also play an important role in the way men approach the disease and how they interact with their spouses.

Although masculinity has been investigated for men undergoing prostate cancer, Brüggemann (2020) noted that studies that investigated masculinity often focused on how masculinity is maintained or redefined in relation to prostate cancer treatment (Brüggemann 2020). Less attention has been given to how men's masculine identity may influence their interaction and communication with their partner during and after completion of prostate cancer

## Discussion

treatment. Gender and masculinity are socially constructed and therefore may vary or change according to the social and cultural background (Connell and Messerschmidt 2005). There is also not a single form of masculinity, a plurality of masculinities exists. Connell (1995) originally identified hegemonic complicit, subordinate and marginalised masculinities, and viewed these as relational and hierarchical (Connell 1995). Hegemonic masculinity is the dominant configuration in its relationship to femininity and its relationship to other masculinities. A more recent development in masculinity is the engagement with feminist theory on care and relationality, and the related development of caring masculinities (Elliott 2016). Caring masculinities are relevant in certain European settings (Elliott 2016), and particularly in the Nordic countries (Nissen 2017).

From the findings of this study, it appears that the majority of men interviewed aligned themselves more closely to traditional gender values, such as hegemonic masculinity. Hegemonic masculine is defined as a set of idealised practices including restricted emotional expression, self-sufficient, power and success, stoicism, heterosexism and misogyny as outlined in Table 10.

*Table 10: Characteristics of hegemonic masculinity (Connell and Messerschmidt 2005)*

<b>Characteristics of hegemonic masculinity</b>
<ul style="list-style-type: none"><li>- Power and success</li><li>- Restricted emotional expression</li><li>- Stoicism</li><li>- Heterosexism</li><li>- Self-sufficient</li><li>- Misogyny</li></ul>

Several of the features, which are characteristic of hegemonic masculinity, were also identified in my study such as a desire of some

## Discussion

men to restrict their emotional expression, stoicism when faced with a potential life-threatening illness such as prostate cancer and the desire to remain self-sufficient. These features also had an impact on how some men reacted to prostate cancer and interacted with their spouses. Findings suggest that men who align themselves with more traditional gender values, often adopted a more individual approach and did not involve their spouses in the pre- and post-treatment pathway. Furthermore, some of these men appeared to struggle more with the impact of treatment related side effects, particularly when these side effects negatively impacted their body image.

A recent meta-synthesis by Bowie et al. (2021) investigated how body image, self-esteem and masculinity affected the QoL of men with prostate cancer. Bowie et al. (2021) noted that men struggled when their diagnosis, symptoms and treatment effects meant they could no longer carry out these 'idealised practices'. These preconceived ideals were held in relation to their ability to function (for example sexually and physically) and how they reacted to illness (for example not seeking healthcare or not telling others about their problem) (Bowie et al. 2021). Bowie et al. (2021) noted that men who were more flexible in their ideal of masculinity could re-affirm their sense of masculinity through other areas, or could justify their perceived loss of masculinity, if that was the price for longer life. However, men who were inflexible and aligned themselves to hegemonic masculinity were at a greater risk of suffering from the psychological impact of these changes. Similarly, findings from my study suggested that some men did not seek help even when faced with the negative side effects of prostate cancer treatment (for example: sexual changes or loss in strength). Such an approach may be detrimental for the emotional wellbeing of men and may also negatively impact upon their spouses. Furthermore, findings suggest that men often did not inform more distant friends and relatives about their prostate cancer diagnosis. Such an approach could lead to avoidance of social contact, this could result in social

## Discussion

isolation and as a consequence be detrimental to their emotional wellbeing.

The literature suggests that the men's age at diagnosis may have an impact on their QoL scores (Kurian et al. 2018), younger men may report more significant differences in side effect severity ratings (Winters-Stone et al. 2014), and particularly sexual problems (Chambers et al. 2015) compared with older men following prostate cancer treatment. Although my study investigated men in a relatively similar age range (64-75 years), an important factor for these men appeared to be related to how well their bodies aligned with their ideal self-image rather than their age following prostate cancer treatment. For example, some men considered themselves to be at an age where the physical side effects of treatment (e.g., sexual functioning and fatigue) was less of a concern as they considered themselves at an advanced age (see Section 5.4.4). However, others in the same age range appeared to have more concerns with the key post treatment changes, perhaps because they considered themselves at an age where they should still be able to perform certain activities (for example sexual function and physical changes) (see Section 5.4.4). Consequently, the side effects caused them greater distress. Such findings may therefore indicate that it is not necessarily the age of the participants that influences their concerns with the experienced side effects, but rather how men perceive their body image aligns with their ideas of 'healthy' or 'successful' ageing. Some of the men could have been justifying the changes not only due to the prostate cancer, but also due to their advanced age (Bowie et al. 2021) and these men could reason that such changes would have happened to them regardless of prostate cancer.

The consequences of prostate cancer treatment may therefore cause a misalignment of their perceived ideal self-image, these men may be trying to hold on to their past lives, the one they had prior to prostate

## Discussion

cancer diagnosis and treatment. In fact, some of the men in my study who appeared to be struggling more with the consequences of prostate cancer treatment, more often compared their situation with their pre-treatment physical functioning (see Section 5.6.4). Some men may be stretching their sexual activity and physical fitness ideals into higher ages groups (Calasanti 2016). Such findings have also been suggested by Pudrovska (2010) who investigated gender differences in psychological adjustment to cancer (including breast, prostate, colorectal and lung) amongst older white adults. Pudrovska (2010) noted that men who more strongly upheld male identity were more likely to report depressive symptoms than their peers (Pudrovska 2010). Such an approach may cause a conflict between retaining their masculine ideals and accepting their new lives where this is no longer possible. This can result in men struggling to accommodate their illness, leaving them distressed, angry and sometimes depressed (Bowie et al. 2021).

A prostate cancer treatment may threaten the masculine identity of men and findings indicate that there is a lack of psychosexual support for these men and their partners. There is a need to improve the support of men and their spouses following prostate cancer treatment and hegemonic masculinity may prevent men from seeking support or assistance.

### 6.3.2.2. Female spouses and prostate cancer

Prostate cancer patients often depend on their spouses for emotional and practical support during and following treatment (Nelson et al. 2019), with similar findings noted in my study. Some spouses may approach the caregiver process with more sentiment and emotions and they may view this caring process not as something new but rather as an extension of their feminine role, when the spouses are female (Calasanti and Bowen 2006). Although spouses may be an important support structure for men following treatment, providing support and

## Discussion

assistance to their men was emotionally challenging and their needs were not adequately addressed by healthcare professionals.

To better support their husbands several engagement strategies were identified in this study, and it was often the spouses that initiated shared or common strategies. For example, including a range of different activities to ensure that the men maintained wider social contact and using some form of distraction to 'get their partner out of the house'. Such engagement strategies have also been identified by Collaço et al. (2021), who investigated the experiences and needs of younger men (<65 years of age) and their partners following prostate cancer treatment (Collaço et al. 2021). Collaço et al. (2021) identified that prostate cancer diagnosis and treatment triggered different engagement strategies and behaviours which pertained to how couples interacted with one another including distraction. Distraction was a helpful coping strategy for couples in the Collaço et al. (2021) study as it allowed them to 'put cancer at the back of their minds'. The most common form of distraction identified by Collaço et al. (2021) for men and their spouses included work-related activities. Although in this study, some men and their spouses were still involved in work related activities, most participants were retirees and this would make it more difficult for them to benefit from such a coping strategy. In fact, findings from this study indicated that men and their spouses often had to find new forms of distraction, certain activities were no longer possible due to the side effects caused by prostate cancer (for example loss of strength, urinary side effects). Spouses were often the ones to initiate new activities in which to engage their husbands and therefore highlighted the important role that they may play in their husbands' recovery process. In addition to providing suitable distractions, some activities also involved friends and relatives, and this may also benefit the social well-being of the couple.

O'Brien and Steele (2017) also observed that female partners of prostate cancer patients often considered themselves as having a

## Discussion

'natural instinct' to care for others, and some female spouses may also view this as their duty (Ervik et al. 2013). Women have traditionally been encouraged to be interpersonally orientated and to attention to others' emotions (Powell and Greenhaus 2010). Although some spouses may adopt a more traditional female role as the provider of support and care for their husbands, assuming traditional caregiver roles may have an emotional costs for them (Chambers et al. 2013). In fact, several spouses in my study noted the negative impact the prostate cancer experience had on their emotional well-being, which was often not addressed by healthcare professionals.

As prostate cancer is a male specific condition, spouses' needs may be less visible, they may not therefore be sufficiently addressed by health professionals. Such 'invisible needs' were identified by Midtgaard et al. (2021) who explored partners' experiences of prostate cancer patients' engagement with a community-based football programme. This study employed eight focus groups with a total of 39 female partners of men with prostate cancer. Midtgaard et al. (2021) identified that women had 'invisible needs', as some felt lonely and exhausted at times. According to Midtgaard et al. (2021), spouses commonly reflected 'the feminine ideal' of caring and compassion (that is caring, nurture, collaboration, touch and talk), these could be seen to be in contrast to the men (that is competitiveness, physical power). Similar findings have been reported in my study, in that woman often highlighted their caring and nurturing role in supporting their husbands. However, such a commitment comes at an emotional cost for spouses, this often became apparent after the completion of prostate cancer treatment. In fact, several spouses commented that the experience was emotionally demanding, and some were struggling to deal with their husbands and their own emotional needs. Furthermore, there appears to be a lack of acknowledgement, or exploration, by healthcare professionals to assess the impact of a prostate cancer treatment on spouses. This is likely to lead to unmet supportive care

## Discussion

needs and may be detrimental to their ability to adjust to the impact of prostate cancer treatment.

Healthcare professionals should therefore also assess the impact of prostate cancer on spouses in order to identify their supportive needs. This is of particular importance as couples in my study usually did not disclose their diagnosis to friends and family, they therefore largely had to rely on each other for support. How couples experience and react to a life-threatening illness appears to be strongly related to their gender role, with men trying to take control of their illness and spouses taking a more a supportive and caring role. Such gender roles may be shaped and influenced according to the social and cultural background; this is further discussed in the following section.

### 6.3.3. Social and cultural influence of couples dealing with prostate cancer in Malta

According to Gotay (2002) culture affects how individuals view themselves in relation to others, including how they view illness and how they cope with stressful life events. Within Malta and the Mediterranean region, the conventional household composition and the role of the family as a welfare agency differs from those observed in Northern Europe (Kalmijn and Saraceno 2008). For example, Fiorillo and Sabatini (2015) emphasise the importance of the extended family as an institution, it operates across generations and over a broad family network in Southern Europe and in Italy. Similar findings have been reported in the literature for local Maltese settings. Satariano and Curtis (2018) investigated the social determinants of health within a Southern European Maltese culture. This study adopted a purposive sample of ten families comprising parents and children from three different deprived Maltese neighbourhoods. Interestingly, most men refused to participate in this study. The researchers suggested that this might indicate their 'machismo', they may have been reluctant to discuss their difficulties or weaknesses with a female interviewer



## Discussion

(Satariano and Curtis 2018). Satariano and Curtis (2018) identified two main themes: the role of the extended family and family honour, religion, and gender norms, they suggested that the extended family may have an important role in providing support particularly when problems (for example health or financial) arise. However, findings from my study do not support this notion and suggest that support from the extended family was limited. This was largely because couples (and men in particular), avoided wider disclosure about their illness with extended family, perhaps because of the perceived potential stigma associated with the condition.

There is some evidence to suggest that cancer stigma prevents men from seeking wider help and support (Hyde et al. 2017) and that men are reluctant to disclose their diagnosis due to stigma associated with the disease or its side effects (Gray et al. 2000; Ettridge et al. 2018). Although the reason for a lack of disclosure to the extended family was not always clear, some couples noted that they felt a prostate cancer diagnosis was not something that you should tell everyone, some couples preferred to keep such information private. Other men mentioned that they limited the disclosure as they did not want to be pitied by others. This indicates that cancer stigma may be present in the local setting and that may hinder open communication. A local study performed by Briguglio and Tedesco (2016) investigated how cancer patients interact with family members and society. Briguglio and Tedesco (2016) performed semi-structured qualitative interviews with 11 former cancer patients. This study suggested that the cancer experience had a mixed impact on the participants' interactions in social life. While some participants withdrew from social interactions, others continued with their normal social interactions. Although most of the participants in the study by Briguglio and Tedesco (2016) did not feel stigmatised by others, this was mainly because they did not disclose their illness to non-family members as they feared the social repercussions of being exposed. The authors therefore suggested that

## Discussion

the spectre of stigma may have haunted the participants of this study (Briguglio and Tedesco 2016). Although Briguglio and Tedesco (2016) included 11 former cancer patients, only 3 were men and only 1 was diagnosed with prostate cancer. Therefore, these findings may not be entirely representative for couples dealing with prostate cancer in Malta.

Couples therefore often had to rely on each other and/or direct family members (for example children). When couples, and in particular spouses, are overwhelmed with the tasks and responsibilities of giving care to their men, it can result in emotional distress (see Section 5.6.5.). In the wider literature this has been termed 'caregiver burden' (Adelman et al. 2014) and may lead to long-term distress for the spouses supporting men affected by prostate cancer (Hyde et al. 2018). The emotional wellbeing of men and their spouses is therefore an important area which may require additional consideration from healthcare professionals in the local setting.

Cultural and social factors may influence how couples' approach and deal with the consequences of prostate cancer. An important factor that was identified in the local setting and which may support couples in coping with the negative consequences of a prostate cancer treatment is religion and their religious beliefs. The use of prayer, and the feeling that others were praying for their health, supported the couples in my study and had a positively impact on their emotional wellbeing. In addition, members of religious groups were also indicated as an important source of support during and after prostate cancer treatment. Religion has been identified in the literature as an important coping strategy for managing stress (Bruce et al. 2020), this was also noted in my study. Religious beliefs also meant that some couples believed their destiny was out of their control and 'in God's hands', this enabled the couples to cope better and to adjust to the impact of prostate cancer. Spirituality and faith have been identified as

## Discussion

an important coping resource in a local study performed by Baldacchino et al. (2012). This descriptive explorative study investigated illness appraisal and spiritual coping of three groups of individuals with life-threatening illnesses, one of the groups included cancer patients. For cancer patients faith in God was found to be a coping resource, it helped them turn the negative experiences into positive outcomes for the future (Baldacchino et al. 2012). In addition, prayer was found to be a personal connection with God who helped them to get through the hardships of their illness (Baldacchino et al. 2012).

Religious beliefs and support from religious institutions can therefore be an important resource, it can aid a couple in their efforts to deal with the illness. In addition, interacting and meeting members of religious institutions may also benefit the social functioning of couples. Healthcare professionals in the local setting need to be sensitive to the role of religion and faith, it could be seen by healthcare providers as a potential opportunity for improved outcomes.

The wider cultural background in which this study took place may also have influenced the interviews and the nature of disclosure of the participants during the interviews. Although, as outlined in 4.7.4., I adopted several strategies to enhance the reciprocal nature of the interview setting, some participants may have been reluctant to disclose some aspects of their prostate cancer experience. Although there appears to be a lack of evidence regarding the impact of cultural factors on the nature of disclosure in interviews, local news articles may provide some further details.

A local newspaper article suggest that individuals in the local setting may be reluctant to disclose the emotions to others following a cancer diagnosis and treatment (Grech 2018). While the man in the article was diagnosed and treated for lymphoma, he indicated that he was always taught that he could not express what he felt, especially if he

## Discussion

was afraid or in pain. In addition, he mentioned that he could not speak openly about what he was feeling and he admitted that he forced himself to go about life as though everything was normal. Such behaviour could make it difficult to identify the emotional impact or needs in the local setting. The article indicated that there may be a larger societal problem where people in particular men, were taught they could not speak out about their fears (Grech 2018).

In addition, sexual health or discussions of sexual health in the local setting may also be not routinely disclosed or discussed due to the cultural sensitivity in the local setting. For example, some couples in my study indicated that healthcare professionals did not adequately address their sexual concerns.

While research in the local setting is limited, a recent newspaper article suggest that sexual health policies are outdated (Tortell 2022). In some countries, such as India, it has been reported that clinicians are often hesitant discussing sexual health with older patients as they consider this a taboo (Chatterjee 2019). Similarly in the local setting, a recent video uploaded on a social media platform by a sex therapist in Malta also suggest that sex remains a taboo in Malta (Bartolo 2022).

Although there appears to be a lack of research regarding sexual health or discussions of sexual health in the local setting, a recent newspaper article suggest that sexual health policies are outdated (Tortell 2022). In addition, although initiative to improve the quality of life of Maltese citizens were highlighted in the 2022 annual state budget, sexual health was not included (Tortell 2022). This may therefore suggest that sexual health may be overlooked and not adequately addressed following prostate cancer treatment.

Several theoretical frameworks have been developed, these could provide a framework to better understand how couples cope and adapt to prostate cancer. These are discussed in the next section.

## **6.4. COUPLES COPING WITH STRESS**

A life-threatening illness, such as prostate cancer, exposes couples to increased risk of physical and emotional problems (Varner et al. 2019; Manne et al. 2021). These are probably a result of multiple stressors accompanying the illness (Falconier et al. 2015) and the demands that they can impose on couples (Applebaum and Breitbart 2013). There is evidence to indicate that patients and partners distress levels are highly related and the distress levels of one partner can significantly impact the other (Wootten et al. 2014). 'Dyadic stress' is often used to describe stress that both partners experience when faced with a common threat, such as cancer (Bodenmann 2005a). 'Dyadic coping' refers to a couple's response and the strategies that generally reflect the goal of dealing with dyadic stress.

As research on the impact of, and coping with, a serious illness such as cancer has developed using individual experiences of couples and families, many theories have been proposed that capture a couple's adjustment to and coping with illness related challenges (Regan et al. 2015).

Early models of stress and coping, such as Lazarus and Folkman's transactional model (Lazarus and Folkman 1984), focus on the individual's ability to appraise and manage competing demands. The assertion that stress and coping are not independent of their partners' stress represents a relational process that is a cornerstone of modern dyadic coping concepts (Bodenmann 2005a). Several key dyadic coping models have been proposed and are briefly discussed below.

### **6.4.1. Models of dyadic coping**

One line of coping related research emphasises congruence or discrepancy between the partners' coping efforts, it analyses the effect of similar versus different individual coping strategies (Revenson 1994). Coyne and Smith (1991) expanded upon Lazarus' transactional

## Discussion

approach by considering partners' coping contributions to the other partner's wellbeing. They distinguished three forms of relationship-focused coping: active engagement (for example involvement of the partner in discussions, inquiring how the partner feels and instrumental or emotional engagement), protecting buffering (for example providing emotional relief to the partner and hiding concerns from the partner) and overprotection (for example dominance, aggressive or submissive strategies to avoid strong emotional involvement) (Coyne and Smith 1991). However, this model was developed in the context of couples dealing with one partner's severe illness and where illness was defined as a shared fate (Coyne and Smith 1991). Therefore, this model may be less relevant when the ill person does not consider their illness to be a shared burden.

The Systemic Transactional Model (STM) by Bodenmann (1995), is based upon the interdependence between partners' stress and coping and assumes that one's partner's daily stress experience and their behaviour under stress and well-being also have a strong and frequent impact on their partner's (Bodenmann 2005a). According to the STM model, partners' well-being is strongly intertwined, and their happiness is dependent on one another. The STM model suggest that couples' coping involves a reciprocal interplay between stress communication and positive and negative coping responses (Bodenmann 2005a). However, within this model there is limited exploration how individual development factors may influence a persons' interaction with their spouse.

Another theoretical model that has been proposed to explain the process of couples coping with cancer include Manne and Badr's relationship intimacy model of couple's psychosocial adaption to cancer (Manne and Badr 2008). This dyadic coping model focuses on behaviour, which contributes in two ways: relationship enhancing behaviour or relationship compromising behaviour. According to this model, three relationship enhancing processes have been identified,

## Discussion

namely: reciprocal self-disclosure, partner responsiveness and relationship engagement (Manne and Badr 2008). In addition, three relationship-compromising behaviours have been proposed for this model, namely avoidance, criticism and pressure-withdraw (Manne and Badr 2008).

Whilst my study also identified relationship-enhancing and relationship-compromising behaviour, these behaviours were often adopted following the appraisal process, which is not specifically incorporated in this model. For example, couples that appraised the illness as a 'shared' concern adopted more relationship-enhancing behaviour, such as self-disclosure and relationship engagement. However, couples that appraised the illness as an individual concern often adopted more relationship-compromising behaviour such as avoidance. In addition, the model by Manne and Badr (2008), does not include or acknowledge how contextual or development factors may influence the adjustment of couples.

Of particular interest for this study is the Development Contextual Model (DCM) of dyadic coping (Berg and Upchurch 2007). This model is theoretically close to the STM model regarding shared appraisal and common dyadic coping, but it extends this model in relation to the context of chronic disease. According to the World Health Organisation, chronic diseases or noncommunicable diseases tend to be of long duration and are the result of a combination of genetic, physiological, environmental and behavioural factors (World Health Organisation 2022b). The main types of noncommunicable diseases are cardiovascular disease, cancers, chronic respiratory diseases and diabetes (World Health Organisation 2022b). The DCM model which has been extended for chronic illness such as cancer, may therefore be relevant to better explain the dyadic coping process.

The DCM model places the coping process in a developmental and historical perspective regarding the different stages of dealing with

## Discussion

disease across the lifespan (for example young couples, middle-aged couples and late adulthood) and historical times (for example historical changes in women's status and roles may make gender differences less apparent in younger cohorts when compared to older cohorts). Berg and Upchurch (2007) suggested that dyadic coping may vary according to these factors, especially in relation to the stage of the disease (e.g., coping with initial symptoms, coping with treatment and daily management), but also sociocultural aspects (for example health-beliefs, perceptions of symptoms, role division, individualistic versus collectivistic orientation). Dyadic coping is further shaped by gender, marital quality, illness ownership and illness severity. Thus, a complex set of variables is considered in the prediction of dyadic coping in the context of chronic illness.

The DCM model of Berg and Upchurch (2007) suggests that dyadic coping is influenced by a complex set of variables, this has also been identified in my study. For example, as outlined previously, gender and sociocultural norms may influence how couples appraise and adopt different individual or dyadic coping strategies. Dealing with an illness such as prostate cancer across the lifespan can affect a couple's ability to cope with it. Furthermore, as my findings demonstrate, the demands of prostate cancer vary over time, from pre-treatment until the development of longer-term side effects which can occur some point after the completion of treatment. Previous research indicates that gender may influence patients' preferences concerning health care (Weber et al. 2019), communication relating to cancer (Lim et al. 2015) and distress in coping with cancer (Gallagher et al. 2019). Similarly, my study suggests that gender plays an important role in adjusting to prostate cancer. In particular, this study suggests that men commonly align themselves to their 'masculine identity' and their spouses to a more traditional 'feminine, caring and supportive role', this appears to influence their coping and adjustment to the illness. These gender identities are shaped according to the sociocultural



## Discussion

background in which the couple interact. Berg and Upchurch (2007) noted that sociocultural factors affected the norm and expectations for the level of interdependence amongst spouses. Interdependence refers to how an individual's identity is embedded in their interpersonal relationship or is separated from their relationship. Couples who see themselves as part of a collective unit (their sense of 'we-ness'), can typically cope more effectively with a stressor (Berg and Upchurch 2007).

More recently, Badr and Acetelli (2017) have proposed the Cognitive-Transactional Model which synthesises the DCM and STM model by describing the circumstances in which individuals in a relationship may engage in individual or dyadic coping as well as the process by which couples negotiate coping. According to Badr and Acetelli (2017), one of the limitations of the DCM model is that it does not directly address the interplay between individual and dyadic coping efforts. According to Bodenmann's STM model of couples coping with stress, requires one partner to be experienced this stress and emphasizes the transactional nature of the coping process. Bodenmann further describes a stress-cascade process whereby individual and dyadic coping efforts come into play and are applied in sequence (Bodenmann 2005b). Following the onset of stress, individuals start coping on their own, however, in cases or prolonged distress, individuals seek out social resources and engage in dyadic coping. My study however did not identify an interplay between individual and dyadic coping efforts and therefore the CTM model was not deemed as the most appropriate model to explain the dyadic coping efforts. However, it should be noted that my study adopted a cross-sectional design and therefore prolonged engagement with stressors may not have occurred at the time of my study and therefore the interplay between individual and dyadic coping efforts could occur at a later stage.

## Discussion

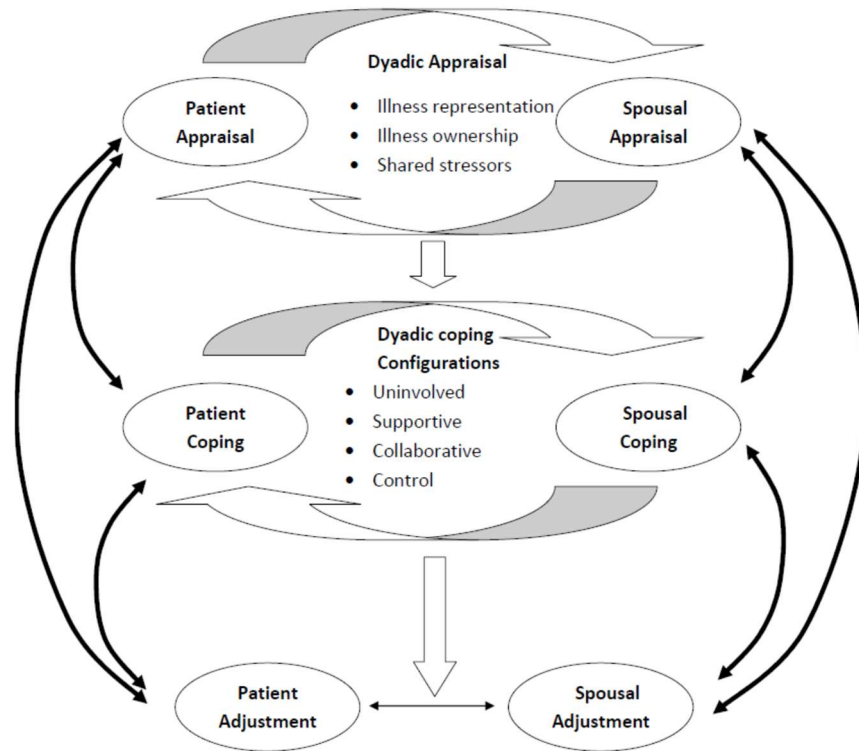
Berg and Upchurch's (2007) DCM describes how contextual factors, dyadic appraisal, and dyadic coping affects patients' and partners' adjustment to chronic illness. This framework was therefore used to provide further insight into how couples adjust to prostate cancer, and this is further discussed in the next section.

### 6.4.2. Development Contextual Model (DCM)

DCM views chronic illness as affecting not only the patients but also their partners, "as they are mutually involved in each other's stressors" (Berg and Upchurch, 2007, p. 933), it therefore requires both patients' and partners' assessments of appraisal, coping, and adjustment. Further, the DCM suggests that patients' and partners' assessments of contextual characteristics, appraisal, and coping and adjustment are correlated (see figure 7). While some of the contextual factors have been discussed previously, this section further discusses dyadic appraisal and dyadic coping.

## Discussion

Figure 7: Dyadic appraisal, coping and adjustment (Berg and Upchurch, 2007)



### 6.4.2.1. Dyadic appraisal

Berg and Upchurch (2007) examined three aspects of the dyadic appraisal, illness representations, illness ownership, and shared stressor appraisal. Illness representation includes the representation of the illness (for example controllability and consequences) and how couples manage uncertainties regarding illness (Goldsmith 2009). Another component in the dyadic appraisal is illness ownership or how the illness is 'shared' between the couple (for example does the illness 'belong' to the patient or is it collectively 'shared' between patient and spouse).

## Discussion

### 6.4.2.2. Dyadic coping configuration

The DCM model examines the dyadic coping strategies of both patient and spouse, they are mutually involved in each other's stressors. Examining the marital dyad as a unit allows for the identification of dyadic configurations of coping (for example 'invisible support', in which the patient views their spouse as uninvolved but the spouse reports providing support (Bolger et al. 2000). Dyadic coping and adjustment are part of a transactional process that unfolds over time, such that multiple directions of influence are involved (for example not only does patient and spousal dyadic coping affect patient and spousal adjustment, but adjustment may subsequently affect future dyadic coping efforts).

### 6.4.3. Application of DCM model to my study

The DCM model may provide a useful framework to outline how couples appraise, cope and adjust to a prostate cancer diagnosis and treatment. In this section I will propose how the findings from my study may be applicable to this model and the implication for couples and healthcare professionals. Furthermore, I will propose how contextual factors such as age, gender and culture may influence the dyadic coping process.

#### 6.4.3.1. Dyadic appraisal

One major component of the DCM model is dyadic appraisal between partners. Berg and Upchurch (2007) examine three aspects of dyadic appraisal including illness representations, illness ownership, and shared stressor appraisal. These different components of dyadic appraisal are discussed in more detail in relation to my findings and what this could mean for couples and healthcare professionals.

### **Illness representation**

Illness representation in the DCM model relates to the implications and outcomes of the illness and how uncertainties surrounding the illness should be managed. According to the DCM model, illness representation refers to similarities between the men and woman regarding the controllability and consequences of such illness. Although men undergoing prostate cancer treatment have excellent survival rates (Ferlay et al. 2021), men may suffer from a range of treatment related consequences that can have a negative impact on their quality of life (Adam et al. 2018). Findings from this study indicate that men and women often held similar views regarding illness controllability; however, some dissimilarity was noted in their appraisal of the consequences of prostate cancer and/or treatment related side-effects (see Section 5.6.1). Disagreements in the illness representation often occurred amongst couples after the completion of radiotherapy treatment. For example, some of the men experienced minimal side effects immediately after completion of radiotherapy treatment. This may have subsequently influenced the couple's illness representation, in that the illness was apparently 'controlled and had minimal consequences'. However, the reality was that these men experienced the greatest consequences sometime after the completion of radiotherapy treatment. In particular, the side effects that appeared to have the greatest impact on men's day-to-day functioning included fatigue and loss of strength, which limited their mobility. In addition, such side effects may be more difficult to personally comprehend, as they are often not directly visible to others, besides the person experiencing it. Consequently, such side effects could lead to differences in the illness representation between men and their spouses and differences in illness representation may be detrimental for the dyadic coping efforts (Merz et al. 2011; Lyons and Lee 2020).

## Discussion

Illness representation may therefore be an important aspect for healthcare professionals to consider. In fact, findings from my study indicate that not all participants were aware of the timing and/or severity of the side effects of prostate cancer treatment. This therefore highlights the importance of healthcare professionals including, where possible, men and their spouses in the discussion and provision of information. This may lead to a better understanding of the consequences (particularly in the longer term) of the treatment. In addition, some couples were minimally involved in the treatment-decision making process and left the decision to the specialist. Such an approach can lead to a lack of understanding of the timing and severity of side effects, this could lead to a misalignment in the illness representation between men and their spouses. A misalignment in the illness representation may be detrimental for the emotional wellbeing of couples and could hinder dyadic coping efforts (Badr 2022). Healthcare professionals should therefore try to actively involve both men and spouses, where possible, in the provision of relevant information and in the treatment decision-making process. Such an approach could reduce some of the misconceptions identified in my study and lead to a better alignment in illness representation which could positively impact upon their emotional wellbeing and quality of life (Merz et al. 2011; Lyons and Lee 2020).

### **Illness ownership and shared stress appraisal**

Illness ownership, as outlined in the DCM model, refers to whether couples appraise the illness as a 'shared' or 'individual' concern. Appraising the problem as a shared concern may be a starting point for collaborative coping efforts (Berg et al. 2008). Shared stress appraisal refers to whether couples appraise the specific stressor resulting from the illness as a shared or individual concern. My study suggests that couples who appraised the illness as a shared concern also appraised the different stressors from a dyadic perspective. This

## Discussion

therefore could indicate a close relationship between these appraisal aspects as identified in the DCM model and therefore these will be presented together in this section.

According to the DCM model, a patient may initially appraise the illness as 'mine' but repeated daily discussions with their spouse, regarding the stressor, may be associated with changes towards a more shared illness appraisal. However, findings from my study suggested that illness ownership and shared stress appraisal are closely connected, with no apparent changes between diagnosis and post-treatment regarding the illness appraisal. This may be explained by the close relationship of the different communication patterns identified in a 'shared' or 'individual' illness ownership approach.

My study revealed that some couples appraised the illness as a shared concern, whilst others, particularly the men, appraised the illness as a personal concern (see Section 5.4.1). Appraising the illness as an individual concern influenced the couple's dyadic coping efforts. These men commonly tried to hide their emotions from their spouses and involved them minimally in the prostate cancer process. For example, these men attended all the appointments and treatment sessions alone and commonly avoided cancer-related discussions with their spouses. They also commonly believed that they had remained 'strong' and unaffected by the illness in front of their wives and others. Such an approach appeared to be strongly related to hegemonic masculinity (see Section 6.3.2.1.) which may therefore influence men's perceptions of illness ownership. However, dealing with the impact of the illness individually may adversely affect couples' abilities to adequately support each other (Collaço et al. 2018). In fact, my study indicates that men who adopted a more individual illness appraisal, also adopted more individual coping efforts. Consequently, some spouses felt uninvolved in the prostate cancer recovery process (see Section 5.5.1). Couples who adopted a more individual approach in

## Discussion

their efforts to cope with the consequences of cancer may have impeded their relationship functioning (Traa et al. 2015).

One of the key aspects for a dyadic appraisal in the DCM model is illness ownership or the perceptions of couples to perceive the illness as a shared stressor. In the wider-literature different terms have been used to describe 'illness ownership' in prostate cancer. Collaço et al. (2021) refers to this as the couples' sense of 'us' or 'we-ness'. Similarly, Fergus (2011) indicated that intimate partner's ability to consistently adopt a 'we' outlook in relation to cancer has been associated with optimal adaption to couples. Similar approaches were identified in my study, and it was identified as 'shared perspective' in dealing with prostate cancer (see Section 5.6.2.). Furthermore, couples who appraised the illness as a shared concern often highlighted the importance of their marriage, they linked this to the religious vows they made to each other indicating the importance of religion in the local setting which may influence the dyadic coping efforts. Furthermore, these couples often had more meaningful cancer-related discussions and this could be beneficial for the relationship. In fact, one couple commented that the entire experience brought them 'closer' as a couple (see Section 5.6.2). This indicates that appraising the illness as a shared concern may be beneficial for the dyadic coping efforts of couples.

Illness ownership may also be an important aspect to consider for healthcare professionals. Findings from my study suggest that spouses were often excluded from pertinent consultations with healthcare professionals. In addition, even less effort appeared to have been made by healthcare professionals in assessing the psychosocial impact that prostate cancer had on couples. Recognising the dyadic impact and involving spouses in relevant prostate cancer discussions, especially in relation to the assessment of treatment impact, may better facilitate dyadic appraisal and dyadic coping



## Discussion

efforts. Improving the dyadic coping efforts of couples is important, it has been identified that this predicts relationship satisfaction (Falconier et al. 2015) and may reduce the stress levels of men and their spouses (Shrout et al. 2020).

### 6.4.3.2. Dyadic coping configuration

The coping efforts, as outlined in the DCM, are arranged along a continuum of involvement, from no spousal involvement (patient perceives that he or she is coping individually) to over spousal involvement (for example patient perceives the spouse as controlling) (Figure 7). This model includes four broad categories of the ways in which individuals may perceive others to be involved in their own coping efforts: no involvement (person perceives that he or she is coping individually with the stressful event), support (spouse provides emotional and/or instrumental support), collaboration (spouse is more actively involved through joint problem solving), or control (spouse dominates the actions of the other spouse by taking charge and telling the other person what to do).

Findings from my research indicated that spousal involvement in the coping process varied between couples. Some men perceived their spouses to be uninvolved, this was mainly due to the man's preference to take perceived personal control of the illness, possibly to protect their spouse from the related negative consequences. Although these men did not directly involve their spouses, some men noted that their partners still provided support, where possible, to their husbands (see Section 5.4.2.). Explicit or 'visible' acts of support from a close partner may represent reparative work, potentially signalling problems in the relationship (Zee and Bolger 2019). This may be particularly relevant for couples dealing with prostate cancer in which the men wanted to 'take personal control of the illness' as identified in my study. However, excluding the spouse could be problematic for relationship satisfaction and dyadic coping efforts. Although not specifically identified in my

## Discussion

study, Bamidele et al. (2019) noted that when spouses felt isolated and excluded from their husbands' prostate cancer journey, they experienced distress. This distress was due to their husband's lack of recognition of the psychological impact the prostate cancer had on them. In addition, spouses that were more closely involved, such as in a supportive or collaborative dyadic coping strategy as outlined in the DCM model, may also be emotionally impacted due to the demands on their own personal wellbeing (see Section 5.5.4.). Therefore, the dyadic coping strategies adopted by couples may lead to different emotional needs for men and spouses and therefore are important to consider for healthcare professionals providing care to couples affected by prostate cancer.

In addition, the DCM model acknowledges that developmental and contextual characteristics may influence the way couples appraise and cope with illness and these are further discussed in the next section.

### 6.4.3.3. Developmental and contextual factors

Findings from my study suggest that developmental and contextual factors may be important in the appraisal and coping efforts of couples. The occurrence of prostate cancer may also vary in relation to the developmental age of the participants, which may influence the illness representation. In addition, gender and cultural factors may also have an impact on the dyadic coping efforts and these are further discussed in this section.

#### **Development age**

According to the DCM model, life-span development difference which occurs in the marital relationship may influence the dyadic coping efforts (Berg and Upchurch 2007). In particular it has been suggested that coping abilities increase with age, with older couples presenting better emotion regulation and making use of more effective collaborating skills (Acquati and Kayser 2019). Although my study

## Discussion

included men of a relatively similar age group (64 – 74 years) and their spouses, some differences were noted in the application of coping efforts when compared with Collaço et al. (2021) whose study included younger couples (less than 65 years of age). Findings of my study revealed that distraction was a common approach adopted by the couples. Distraction enabled them to place the cancer at the back of their minds and therefore aided their coping efforts. Although participants in the study by Collaço et al. (2021) were often still in employment, which allowed them to be distracted, couples in my study were often retired and had to find other areas to take their minds off the illness. Additional efforts were therefore made by some couples in my study to help distract them from (and/or cope with) the challenges associated with prostate cancer (for example holiday planning and/or new hobbies and activities).

Another factor which could have influenced the dyadic coping efforts is how illness representation varies with age. As discussed previously (in Section 6.4.3.1.), illness representation refers to how couples perceive the controllability and consequences of the disease. In particular, it appears that some older men in my study perceived the consequences of prostate cancer as less of a concern to themselves and their spouses. In fact, several men commented that due to their perceived advanced age, they had less concerns with the treatment side effects they were experiencing (see Section 6.3.2.1). Therefore, age may be an important factor which influences the appraisal and coping efforts of couples.

### **Gender and sociocultural factors**

Gender and the sociocultural background may influence the appraisal and coping efforts of couples in the local setting. In particular gender and the role that men and women have in the local socio-cultural setting may shape their adjustment to prostate cancer. It appears that couples in this particular age group follow more traditional views

## Discussion

regarding the role and status of men and women (see Section 6.3.2). These views may have influenced the appraisal and coping efforts, in particular the fact that men more commonly assume the role of the head of the family and were often the breadwinners. In fact, as can be seen from the demographics section (table 4, p144), nine out of 14 women were housewives, indicating the more traditional roles adopted by men and women in this study. These traditional roles also indicate that there may be a hierarchy of power within the relationships that impacts upon the dyadic appraisal and coping process.

Another cultural aspect that may influence the couple's adjustment to prostate cancer is the relatively small size of the island and consequently the close interaction with other family members. Due to this it has been suggested that Malta could be considered as a face-to-face community in which anonymity is unusual (Piscopo et al. 2020). This may therefore suggest some of the efforts by the couples, to prevent the disclosure of the cancer diagnosis to their extended family and friends, are a way of maintaining anonymity in the community.

The strong influence of the Roman Catholic faith was also identified in my study and this may have helped some of the couples to appraise and cope with the consequences of prostate cancer. Several of the couples believed that much of what happened in their lives was beyond their control and that they were not therefore in charge of their own destiny. Consequently, maintaining one's religious faith and related practices (e.g., praying and attending mass) were used to deal with some of the stressors associated with prostate cancer.

### 6.4.4. Theoretical frameworks used in other studies and implication of DCM model on healthcare professional

While certain aspects of the impact of prostate cancer on couples have been well researched using in-depth qualitative studies, relatively few

## Discussion

studies have adopted a theoretical framework for their data analysis or the interpretation of findings. However, the use of appropriate theory can assist researchers in better demonstrating the relevance of their work. A theory can also shed further light on data that might be overlooked or misinterpreted (Maxwell 2012). This section discusses the different theoretical models proposed by the qualitative studies identified in the literature review. Furthermore, I will propose what the DCM model could offer to the findings of my study and how it can benefit healthcare professionals supporting couples undergoing prostate cancer treatment in Malta.

### 6.4.4.1. Theoretical models used in qualitative studies

Although several qualitative studies were identified which focused on couples dealing with prostate cancer, only a few of these studies adopted or explicitly referred to a theoretical model to better explain couples' experiences. In addition, in some of the qualitative studies which did include a theoretical framework it was noted that the frameworks did not focus on couples coping with stressors associated with the disease but on related but more specific areas such as their sexual recovery.

Two studies (Beck et al. 2013; Wittmann et al. 2015) specifically focused on the sexual recovery following prostate cancer treatment. Both these studies proposed their own framework to explain the process that couples may undergo following a prostate cancer treatment. Although such frameworks may be relevant for the sexual recovery process, such frameworks cannot be used to explain other aspects of the recovery process.

Nanton et al. (2010) suggested a model of partner activity in prostate cancer, which focused specifically on the partner. Whilst such a framework may be useful to describe how partners of men with prostate cancer deal with the impact, such a model may be less

## Discussion

relevant for providing further insight into the way couples deal with the stressors surrounding prostate cancer.

A self-designed theoretical model 'man in the driving seat' was proposed by Bamidele et al. (2019) following a grounded theory study. This model proposed that men needed to 'own' the illness, this seemed to be closely associated with men's desire to maintain their masculine identity. This model proposed that there appeared to be a hierarchy of power within Black African/Black Caribbean relationships, men were dominantly positioned as the leader and their partner mostly operated from a supportive and 'accepting' position (Bamidele et al. 2019). This model may be relevant for some of the couples who participated in my study, in particular for those couples in which the men tried to take control of the illness and minimally involved their spouse. However, this proposed model may be less relevant for the couples who approached the illness from a 'shared' or dyadic perspective, as identified by other couples in my study.

Two studies (Harden et al. 2006; Collaço et al. 2021) specifically investigated stress and adjustment frameworks in prostate cancer. Harden et al. (2006) adopted the Family, Stress, Adjustment and Adaption model. Although some similarities in the stress appraisal were identified, this model focused on the family unit in the appraisal and adjustment. Such a model may therefore not be relevant for some stressors which are specific to couples, such as stressors associated with dyadic relationships (e.g. impact of prostate cancer on sexual functioning). Collaço et al. (2021) adopted the work of Manne and Badr's relationship intimacy model of couple's psychosocial adaption to cancer (Manne and Badr 2008). This dyadic coping model focuses on behaviour which contributes in two ways: relationship enhancing behaviour or relationship compromising behaviour. According to this model three relationship enhancing processes have been identified, namely: reciprocal self-disclosure, partner responsiveness and

## Discussion

relationship engagement (Manne and Badr 2008). In addition, three relationship-compromising behaviours have been proposed for this model, namely avoidance, criticism and pressure-withdraw (Manne and Badr 2008). Whilst my study also identified relationship-enhancing and relationship-compromising behaviour, these behaviours were often adopted following the appraisal process which is not specifically incorporated in this model. For example, couples that appraised the illness as a 'shared' issue or concern adopted more relationship-enhancing behaviour such as self-disclosure and relationship engagement. However, couples that appraised the illness as an individual concern often adopted more relationship-compromising behaviour such as avoidance. In addition, the model by Manne and Badr (2008), does not include or acknowledge how contextual or development factors may influence the adjustment of couples.

## Discussion

### 6.4.4.2. Implication of the DCM model for healthcare professionals

A key aspect of the DCM model is the appraisal process, this process could also be important for healthcare professionals when dealing with prostate cancer couples. Two components of the dyadic appraisal that may be particularly important for healthcare professionals to consider are illness representation and illness ownership.

Illness representation represents how couples appraise the illness in relation to the outcome and controllability of the illness. Couples in my study noted that healthcare professionals often highlighted the excellent outcomes in relation to survival rates following prostate cancer treatment. Although this is an important aspect to highlight to couples, the treatment can cause a range of treatment related consequences that may impact on the physical and social wellbeing of men and their spouses. In addition, these treatment related consequences may occur after the completion of treatment and may be permanent. However, findings from my study suggest that not all men and their spouses were aware of the timing and outcome of these side effects, this may have caused misalignment of the illness representation which was detrimental for their dyadic appraisal and subsequent coping efforts. Healthcare professionals therefore need to provide up-to-date information regarding the outcome of prostate cancer treatment and its anticipated side effects. Furthermore, information and detail on how these anticipated side effects may impact upon the physical and emotional wellbeing of couples could improve couple's illness representation.

Illness ownership refers to whether couples appraise the illness as a 'shared' or 'individual' concern. Findings of my study indicated that couples who appraised the illness as a 'shared' concern adopted more dyadic coping strategies and appeared to better adjust to the impact of prostate cancer. Although healthcare professionals may not directly



## Discussion

influence illness ownership, acknowledging and including spouses in the provision of information and assessment of outcomes may lead to a more 'shared' illness ownership appraisal. Some spouses noted that they were not routinely involved in the provision of information and assessment of outcomes and such an approach may result in some men appraising the illness as an 'individual' concern. However, adopting a more individual approach could lead to avoidance, this could be detrimental for the cancer-related communication process between men and their spouses. Involving and including the spouse in the provision of information and assessment of outcome could highlight the fact that the illness may not only impact upon the men, it could also have an impact on their spouses and the couple's relationship. Such an approach may therefore lead to a more 'shared' illness ownership and the increased use of dyadic coping efforts.

## **6.5. CONCLUSION**

This chapter discussed the findings from the study in relation to the wider literature, with a specific focus on couples dealing with prostate cancer in Malta.

Couples in my study considered prostate cancer to be stressful, this affected their emotional wellbeing. Several areas within the cancer pathway were particularly stressful, these included the communication process with healthcare professionals prior to treatment, bladder preparation procedures during radiotherapy treatment and dealing with the post-treatment implications of prostate cancer.

Whereas some couples approached the illness as a 'shared' concern, other men largely approached the illness from an individual perspective. Men who appraised the illness as an individual concern appeared to align themselves more closely to traditional gender norms. Gender norms and the local sociocultural setting influenced

## Discussion

how men and spouses appraised and were coping with the consequences of prostate cancer.

The different approaches adopted by couples can be better understood and explained by the Development Contextual Model, this informs the way that contextual factors, dyadic appraisal, and dyadic coping affect patient and partner adjustment.

The next chapter concludes the contribution to knowledge that this thesis has made and makes recommendations for future research.

## **CHAPTER 7. CONCLUSIONS AND RECOMMENDATIONS**

### **7.1. INTRODUCTION**

This chapter begins by reviewing the research aim and the objectives. Such an appraisal will establish whether the study has achieved the research objectives. This chapter also presents my original contribution to knowledge and proposes a dissemination strategy which helps to inform the research findings. Areas for future research and recommendations for clinical practice are also made.

### **7.2. REVIEW OF RESEARCH QUESTION AND OBJECTIVES**

The aim of this research was to explore the experience of prostate cancer treatment from the perspectives of men and their spouses in the first two years following external beam radiotherapy treatment in Malta. The objectives of this study were to explore:

- Experiences of the healthcare system for men and their spouses before commencing external beam radiotherapy treatment.
- Experiences of undergoing external beam radiotherapy treatment for prostate cancer for men and their spouses.
- Men and their spouses' experiences of the follow-up care after the completion of external beam radiotherapy treatment for prostate cancer.
- The impact of an external beam radiotherapy treatment for prostate cancer on the life and relationship of men and their spouses.

## Conclusions and recommendations

A qualitative descriptive methodology was adopted to explore the experiences of men and their spouses after the completion of external beam radiotherapy treatment. The couples reflected on their experiences of the healthcare system, treatment and how they adjusted to the consequences of prostate cancer treatment side effects in their life and relationship. I found that the entire prostate cancer pathway was stressful for men and their spouses, and several specific aspects were of particular concern for these couples. In particular, delays in diagnosis and the provision of information about treatment were a source of distress prior to treatment. During radiotherapy treatment, the bladder filling requirements necessary for treatment were difficult to maintain and some men experienced urine leakage as a result. Following the completion of treatment, a range of side effects were reported such as erectile issues and loss of strength which had a negative impact on the emotional wellbeing of men and their spouses. These issues were not well addressed by healthcare professionals and the follow-up care arrangements did not adequately meet their expectations. The impact of prostate cancer treatment on the life and relationship of couples varied, with some couples dealing with the impact from a more individual approach, and others collaborating more closely together.

I proposed that the DCM model could be used to better understand how couples coped with prostate cancer and its treatment side effects.

### **7.3. ORIGINAL CONTRIBUTION TO KNOWLEDGE**

Although the experience of couples living with prostate cancer has been investigated extensively, my study focused on several aspects that have, to date, been subject to limited research. In particular this study focused on couples undergoing external beam radiotherapy treatment, which is important as around 30% of prostate cancer patients are estimated to receive radiotherapy treatment (Cancer Research UK 2021). However, most relevant studies identified in the

## Conclusions and recommendations

literature review commonly focussed on surgery and/or explored multiple treatment options. My study identified several aspects that were treatment specific, which can significantly influence the experience of couples undergoing this treatment option. Of particular note are the bladder preparation prior to treatment delivery and the timing and severity of treatment related consequences.

The bladder filling preparation for radiotherapy treatment was identified as a significant source of distress for men and only limited evidence is available within the wider literature from men undergoing such preparation. In particular, my study identified that 2 men experienced urine leakage on the radiotherapy unit, which caused significant embarrassment for them, and most men had difficulty in maintaining the required bladder volume. Such findings highlight the importance of taking men's views into account when evaluating prostate cancer preparation procedures. Furthermore, the side effect profile of external beam radiotherapy treatment tends to differ from surgery as identified in the wider literature. Consequently, whereas the greatest side effects from prostate cancer surgery tends to be experienced immediately after treatment, side effects from radiotherapy and/or hormone therapy may occur several months after the completion of treatment. Findings from my study suggested that not all couples were aware of this, it led to misconceptions regarding these side effects and caused disruptions and/or conflict within marital relationships.

My study also focussed on a particular age group (men aged 64-74 years), which allowed the identification of different experiences within this cohort. Whereas distraction was a common coping strategy identified in my study, used to deal with post treatment sequela, the application of this approach within this age group varied from a study that included younger men (age <65 years) who were often still employed (Collaço et al. 2021). In my study, distraction was often initiated by spouses and often related to couples' associated activities

## Conclusions and recommendations

(for example going shopping), which could perhaps enhance relationship closeness and highlights the important role spouses can play in their husbands' recovery.

My study suggest that some couples adopted an individual approach to illness appraisal, whereas other considered the illness as a shared concern. However, individual approaches appear to be detrimental for dyadic coping efforts and can lead to additional distress for men and spouses. Appraising the illness as a shared concern may therefore be an important aspect in the dyadic coping efforts of couples. Findings suggest that the way couples appraised their illness was informed by the socio-cultural norms present in the local setting and this may therefore vary from other healthcare settings and backgrounds. For example, men and woman in this study appear to be following more traditional gender norms that influenced their dyadic appraisal process. In that some men who aligned themselves more closely to hegemonic masculinity adopted more individual approaches in dealing with the consequences of prostate cancer. Findings from my study also indicate that participants' socio-cultural background may influence couples' appraisal and coping configuration. Couples in my study often tried to limit diagnosis disclosure to their direct family members (for example children) and typically avoided disclosure to wider family and friends. Such an approach could lead to changes in the social interactions and potential access to a wider social support network, which may be detrimental for their emotional wellbeing. In addition, faith and religion was identified as an important support resource and coping strategy for couples in the local setting. For example, several couples noted how praying helped them to cope with the negative consequence of prostate cancer. In addition, several couples believed that God was in control of their life, which also helped them to deal with the prostate cancer experience.

## Conclusions and recommendations

Whilst several theoretical frameworks have been applied to couples dealing with stressors surrounding prostate cancer, I have proposed that my findings appear to be strongly related to the Developmental Contextual Model by Berg and Upchurch (2007), which I believe to be unique in this particular context. The DCM model incorporates dyadic appraisal, dyadic coping configuration and dyadic adjustment. According to this model, a chronic illness such as prostate cancer, does not only affect the patient, but affect both members of the couples and therefore their treatment experience. This model suggests that the assessment of appraisal, coping and adjustment are correlated, and this may have important implications for healthcare professionals. For example, the different components, as outlined in the DCM model, could facilitate health professionals to better enhance dyadic appraisal and dyadic coping efforts of couples which may subsequently help to improve couples' dyadic adjustment to the consequences of prostate cancer treatment, thus helping to reduce related stressors.

In addition, the DCM model recognises that dyadic appraisal and coping efforts may be influenced by broad socio-cultural aspects, such as gender norms, interactions with family/friends and religion or religious beliefs (see Section 6.4.3.3). Such findings may therefore be relevant for healthcare professionals to consider when providing support to couples undergoing prostate cancer treatment. For example, men that follow more traditional gender norms often preferred a more individual approach to dealing with the consequences of prostate cancer treatment, which can be detrimental to the dyadic appraisal and coping efforts of couples. This may therefore be an important consideration for healthcare professionals, as these couples may have higher supportive care needs, as they receive less support from within their marriage. In addition, the reluctance to disclose their diagnosis to wider family and friends adversely affected their social and emotional well-being. These couples may therefore require additional support from healthcare

## Conclusions and recommendations

professionals in dealing with the consequences of prostate cancer treatment.

An important support resource that was identified in my study included faith and/or religious beliefs. Couples that utilised such resource appeared to be coping and adjusting better with the impact of prostate cancer treatment. These couples often believed that they were not in control of their illness and that their lives were 'in the hands of God'. However other couples who did not indicated the importance of their faith in dealing with the consequences of prostate cancer treatment appeared to find it more difficult to cope and adjust with the treatment related consequences. Therefore, faith or religious beliefs, in this particular context, may be an important aspect to consider for healthcare professionals, in that they may be important resources in supporting couples throughout their prostate cancer journey.

In addition to these broad socio-cultural aspects that may influence dyadic appraisal and coping efforts, key aspects of the appraisal process as outlined in the DCM model that may be particularly relevant for healthcare professionals to consider are illness representation and illness ownership. Illness representation refers to similarities between men and woman regarding the 'controllability' and consequences of illness. My study identified that dissimilarities were noted in some couples, and these were often related to the consequences of the illness, such as the impact of side effects. In particular, some men noted that they were not able to perform certain physical activities, due to treatment side effects and their spouses appeared to be unaware that these side effects were a result of the prostate cancer treatment. These dissimilarities could have been the result of misconceptions regarding the timing and severity of certain side effects and may therefore have important implication for clinical practice. In addition, several of the men largely left treatment making-decision making to the specialist and were minimally involved in this process. The wider



## Conclusions and recommendations

literature suggests that involving patients and close family members in the treatment decision making process results in higher level of satisfaction with care, can improve knowledge about the condition and longer term consequences of treatment side effects (Stacey et al. 2014; Krist et al. 2017; Martínez-González et al. 2019). This therefore highlights the importance for healthcare professionals to involve, where possible, both men and woman in the treatment decision-making process and the provision of related information. Such an approach may improve couples understanding of the timing and severity of treatment related side effects, notably longer-term sequela, and this may therefore also help to better align their illness representation and subsequently improve their dyadic coping efforts.

Illness ownership refers to whether couples appraise illness as a 'shared' or 'individual' concern. Findings from my study indicate that couples who appraised the illness as a 'shared' concern adopted more dyadic coping efforts and appeared to better adjust to the consequences of prostate cancer treatment. Although healthcare professional may not directly influence illness ownership, acknowledging and including spouses in the provision of information and assessment of outcomes (e.g., distress levels) following the completion of prostate cancer treatment, may lead to a more 'shared' illness ownership appraisal. Some spouses in my study noted that they were not routinely involved in the provision of information and assessment of outcomes. Consequently, such an approach may lead to some men appraising the illness as an 'individual' concern. Better Involving spouses in the provision of information and assessment of outcomes could therefore highlight that the illness not only impacts men but may also affect spouses and the relationship of couples. Such an approach may therefore also lead to more 'shared' illness ownership, which may help inform dyadic appraisal, coping efforts and adjustment following prostate cancer treatment, as outlined in the DCM model.

## Conclusions and recommendations

My study also noted some of the difficulties that some couples have in discussing post-treatment complications with each other. Healthcare professionals could help to bridge such communication gaps by more meaningfully involving men and partners as a collective unit, where possible, when providing pertinent post-treatment support

### **7.4. PUBLICATION AND DISSEMINATION STRATEGY**

The findings of the research have been presented at a post-graduate research symposium organised by the School of Healthcare Sciences at Cardiff University. This allowed me to present my work to post-graduate students and staff members. In addition, the abstract submitted for this symposium has been made publicly available.

It is my intention to publish my findings in key peer reviewed journals to highlight the experiences of couples undergoing external beam radiotherapy treatment for prostate cancer in Malta. A preliminary search has identified the Journal of Cancer Survivorship which I believe would be an appropriate journal for my first findings paper.

I would also like my work to influence the Maltese cancer care. During my studies I have been in contact with the director of cancer care pathways, we have met and discussed some of the key findings to identify potential areas of practice that could be further improved. In addition, this work will be presented at a local cancer conference, the National Cancer Platform organises an annual conference and this would offer the opportunity to present my findings to a broad local audience including healthcare professionals, non-government organisations and the general public. I intend to raise awareness of some of the challenges that couples face in the local setting such as their emotional wellbeing and their sexual needs. This could be tackled in the form of a workshop or continuing professional development (CPD) course for healthcare professionals, including a psychologist and sexologist to outline some of the approaches that could be

## Conclusions and recommendations

adopted to prepare and support couples during and following prostate cancer treatment.

Finally, my findings demonstrated that several men had approached previous cancer patients to obtain additional information and advice from their peers. However, no prostate cancer support group currently exists locally for men and/or spouses. It is my intention to involve relevant stakeholders in Malta to help set up a prostate cancer support group for men and carers. This would be an area that I would like to further explore in future research.

In order to achieve these objectives, the following action plan has been drafted:

*Table 11: Action plan to publish and disseminate findings*

<b>Aim/objectives</b>	<b>Action steps</b>	<b>Proposed timeline</b>
Publication of pre-and post-treatment experiences	<ul style="list-style-type: none"><li>- Identification of journal</li><li>- Writing and submitting a paper for peer review</li></ul>	January 2023 – July 2023
Setting up of Prostate cancer support group	<ul style="list-style-type: none"><li>- Visit a prostate cancer support group abroad (e.g., prostate cancer UK)</li><li>- Involve local organisations such as the male cancer awareness page and national cancer platform.</li></ul>	March 2023 – December 2023

## Conclusions and recommendations

	<ul style="list-style-type: none"><li>- Identifying relevant stakeholders (e.g., patients, healthcare professional)</li></ul>	
CPD course psychosexual needs in cancer care	<ul style="list-style-type: none"><li>- Initial discussions with relevant stakeholders (e.g., psychologist, sexologist)</li><li>- Drafting aims/objectives and learning outcomes for CPD course.</li><li>- Identify lecturers and topics/area to reach aims and objective of course.</li><li>- Submit CPD course to Faculty Board for approval</li></ul>	Course to be offered October 2024

### 7.5. STUDY LIMITATIONS

While the aim of a qualitative study is not to generalise to wider populations, it is possible that some of the findings may be transferable to other relevant settings. Recruitment of participants for this study was difficult and the use of English as the main language for interviews may have resulted in more affluent couples being recruited and therefore may not be representative of all couples in the local setting. In addition, language may also have influenced the narrative as some couples may have found it more difficult to express themselves in English, as outlined in Section 4.11.3.

It was not possible to state that I achieved data saturation but I moved towards this goal (Creswell and Poth 2017). It is therefore possible that there are still some aspects to discover regarding how couples experience a prostate cancer treatment in Malta. However, the

## Conclusions and recommendations

concept of data saturation used in qualitative studies has been questioned. Low (2019) argues that saturation defined as no new information 'is a logical fallacy, as there is always new theoretical insights to be made as long as data continues to be collected and analysed' (Low, 2019 p131). Similarly, Braun and Clarke (2021) argued that attempting to predict the point of data saturation cannot be directly applied to the number of interviews as the meaning and meaning fulness of any themes derives from the data set and the interpretive process (Braun and Clarke 2021).

My interview technique improved as the study progressed. For example, I was initially aware of the use of some leading questions and limited probing of responses, but these were addressed following supervisory feedback and as my experience and confidence grew. Some of the participants also asked me for advice on the management of side effects which I was not prepared for at the time and took some considered management. Some of my earlier interviews may therefore not have generated sufficiently rich data, although this probably also depended on those particular participants. However, I learnt a great deal from this process and it was therefore a very important component of the PhD experience.

### **7.6. RECOMMENDATIONS**

Several key aspects identified in this study may warrant future research and could have implications for healthcare practice in the local setting. The recommendations are divided into clinical practice recommendations and areas for future research.

#### **7.6.1. Clinical practice recommendations**

A common source of distress for couples was the perceived delays in initial diagnosis and treatment. The rationale for such delays was unclear and the couples were particularly concerned that these delays may negatively impact on treatment outcomes. An evaluation of the

## Conclusions and recommendations

current waiting times between initial diagnosis, subsequent investigations and the commencement of treatment could be used to identify areas that are the source of delays. In addition, anticipated waiting times could be communicated to the couples after their initial diagnosis so that they have realistic expectations regarding timing and commencement of treatment.

Several couples experienced a change in their preferred treatment option, this was stressful. Healthcare professionals need to recognise the impact a change in treatment will cause for men and their spouses and such information should be better communicated. Findings from my study noted that such news was commonly given over the phone, with a lack of clear information provided regarding the need for such change. However, a scheduled appointment with the specialist may allow patients and spouses to better understand the need for a change in treatment, it may also help to address any other concerns they have as a result of such a change.

The bladder filling procedure prior to radiotherapy treatment was a common source of distress for the men, with some experiencing urine leakage on the treatment machine. Ensuring a more consistent appropriate approach such as reducing the amount of water intake and/or reducing the waiting time prior to treatment may be more comfortable for these men and could improve their external beam radiotherapy treatment experience.

Findings from my study suggested that spouses were not always involved in the provision of information or the assessment of treatment related outcomes. However, involving spouses in these processes may subsequently benefit couples' dyadic coping efforts and their adjustment to the changes caused by prostate cancer treatment. Therefore, healthcare professionals should, where possible, include spouses in the provision of information and the assessment of treatment related outcomes, where possible. Such an approach could

## Conclusions and recommendations

highlight the fact that side effects from prostate cancer treatment may lead to changes at an individual level (e.g., for the men and spouses) and at a couple's level (e.g., their relationship). Recognising that the treatment may cause changes on an individual but also a dyadic level may lead to a greater dyadic illness appraisal, this may be beneficial to the adjustment of couples following prostate cancer treatment.

Several men gained additional advice from men who had previously received prostate cancer treatment. This information helped them to make their treatment decision and such information may also have helped them after the completion of treatment. Such an approach may therefore also be beneficial for couples dealing with the post-treatment implications of prostate cancer treatment. In particular men may gain additional information and insights as to how to better deal with certain side effects. Such an approach may also be beneficial for spouses who might gain additional support from other spouses.

A recent development during my study was the introduction of a cancer navigation nurse in the local setting. Cancer navigation programs has been associated with several positive outcomes for patients, such as a more timely diagnosis and reduction in healthcare disparities (Rodday et al. 2015). Cancer navigation nurses may provide peer navigation and offer informational, emotional and practical support to new patients and their partner (Fillion et al. 2009). A recent article by the World Health Organisation (2022a) highlighted that the introduction of a nurse navigator in the local cancer care services can bring a personalised, integrated approach to care both during and after treatment. The introduction of such services in the local setting may therefore be beneficial for patients and spouses and future research could investigate the role of the navigation nurse in the provision of personalised care and how this could improve the experience of couples affected by prostate cancer.

## Conclusions and recommendations

### 7.6.2. Future research

Bladder preparation, which has historically been used for the treatment for prostate cancer, was a common concern for men undergoing prostate cancer treatment. Although, more recently some studies have used an empty bladder approach in treating prostate cancer patients (Morrison et al. 2019; Chetiyawardana et al. 2020), these studies did not take into account the feedback of participants and were performed with small sample sizes. Therefore, future research should investigate different bladder filling procedures (including an empty bladder), reproducibility associated with these different protocols and outcome of treatment (e.g., survival and severity of side effects). In addition, such research should include the feedback of participants.

Findings from my study indicated that current follow-up arrangements did not always meet couples' expectations. Several couples commented that the current follow-up appointments were conducted at the local oncology hospital. However, these clinics were often busy which limited couples' ability to ask pertinent questions. In fact, my study suggests several areas in which couples reported unmet supportive care needs, these included informational, sexual and supportive care needs following treatment. Future research could investigate the feasibility and efficacy of different methods of follow-up with couples, to potentially improve their supportive care needs. Alternative follow-up arrangements which could be considered area remote surveillance programme or the involvement of primary healthcare such as the general practitioner, these could be compared with the current follow-up arrangements. Several aspects for future evaluation include such areas as couples' overall satisfaction, evaluation of their unmet supportive care needs, QoL and psychosocial well-being.



## **7.7. CHAPTER CONCLUSION**

This study has provided a better understanding of how couples experience prostate cancer treatment in the local setting. Such information is useful in providing evidence upon which local practices could be evaluated and possibly enhanced further. These are also in line with a recent EU initiative Europe's 'Beating Cancer Plan', which tackles the entire disease pathway including the improvement of the quality of life of cancer patients, survivors and carers (European Union 2021). Furthermore, this information may also serve the local National Cancer Plan which aims to increase the participation of cancer patients in the care process. According to the National Cancer plan, cancer services should be patient-centred and should take into account the patients', families and carers views and preferences (Ministry for Health [Malta] 2017).

In essence, it is likely that this work is one of the first to provide an insight from the perspective of couples undergoing prostate cancer treatment in Malta, thereby highlighting aspects where possible action may be required to ensure improved quality of life for cancer patients and their spouses.

While it is possible that certain findings from my study may be reflective of practices occurring in other settings, caution should be emphasised about the transferability of findings. In fact, it must be acknowledged that the main findings from this study are limited to the setting of couples undergoing external beam radiotherapy in Malta. Nevertheless, this study's findings, as well as the emerging recommendations, are important for local practices and may also be beneficial for other research settings as they may be the first step to informing changes in clinical practice. Such changes could assist in the provision of a patient-centred approach and enhance the

## Conclusions and recommendations

experiences for men and their spouses going through and living with the consequences of prostate cancer treatment.

## REFERENCES

Aaronson, N.K. et al. 1993. The European Organization for Research and Treatment of Cancer QLQ-C30: a quality-of-life instrument for use in international clinical trials in oncology. *Journal of the National Cancer Institute* 85(5), pp. 365–376. doi: 10.1093/jnci/85.5.365.

Abell, J., Locke, A., Condor, S., Gibson, S. and Stevenson, C. 2006. Trying similarity, doing difference: The role of interviewer self-disclosure in interview talk with young people. *Qualitative Research - QUAL RES* 6, pp. 221–244. doi: 10.1177/1468794106062711.

Abufaraj, M. et al. 2021. Differential Impact of Gonadotropin-releasing Hormone Antagonist Versus Agonist on Clinical Safety and Oncologic Outcomes on Patients with Metastatic Prostate Cancer: A Meta-analysis of Randomized Controlled Trials. *European urology* 79(1), pp. 44–53. doi: 10.1016/j.eururo.2020.06.002.

Acquati, C. and Kayser, K. 2019. Dyadic Coping Across the Lifespan: A Comparison Between Younger and Middle-Aged Couples With Breast Cancer. *Frontiers in Psychology* 10. Available at: <https://www.frontiersin.org/article/10.3389/fpsyg.2019.00404>.

Adam, S., Feller, A., Rohrmann, S. and Arndt, V. 2018. Health-related quality of life among long-term ( $\geq 5$  years) prostate cancer survivors by primary intervention: a systematic review. *Health and quality of life outcomes* 16(1), pp. 1–14.

Adelman, R.D., Tmanova, L.L., Delgado, D., Dion, S. and Lachs, M.S. 2014. Caregiver Burden: A Clinical Review. *JAMA* 311(10), pp. 1052–1060. doi: 10.1001/jama.2014.304.

Alfano, C.M., Jefford, M., Maher, J., Birken, S.A. and Mayer, D.K. 2019. Building Personalized Cancer Follow-up Care Pathways in the United States: Lessons Learned From Implementation in England, Northern Ireland, and Australia. *American Society of Clinical Oncology Educational Book* (39), pp. 625–639. doi: 10.1200/EDBK\_238267.

Alibhai, S.M.H. et al. 2015. Long-term impact of androgen-deprivation therapy on physical function and quality of life. *Cancer* 121(14), pp. 2350–2357. doi: 10.1002/cncr.29355.

Allen, C. 1997. Spies like us: When sociologists deceive their subjects. *Lingua Franca* 7(9), pp. 31–39.

Alvesson, M., Hardy, C. and Harley, B. 2008. Reflecting on Reflexivity: Reflexive Textual Practices in Organization and Management Theory.

## References

*Journal of Management Studies* 45(3), pp. 480–501. doi: 10.1111/j.1467-6486.2007.00765.x.

Alvesson, M. and Kärreman, D. 2011. *Qualitative Research and Theory Development: Mystery as Method*. SAGE Publications. Available at: <https://books.google.com.mt/books?id=P4b-bTDAVisC>.

Applebaum, A.J. and Breitbart, W. 2013. Care for the cancer caregiver: a systematic review. *Palliative & supportive care* 11(3), pp. 231–252. doi: 10.1017/S1478951512000594.

Appleton, L. et al. 2015. The impact of prostate cancer on men's everyday life. *European journal of cancer care* 24(1), pp. 71–84. doi: 10.1111/ecc.12233.

Aquilino, W.S. 1993. EFFECTS OF SPOUSE PRESENCE DURING THE INTERVIEW ON SURVEY RESPONSES CONCERNING MARRIAGE. *Public Opinion Quarterly* 57(3), pp. 358–376. doi: 10.1086/269381.

Araújo, J.S. and Zago, M.M.F. 2019. Masculinities of prostate cancer survivors: a qualitative metasynthesis. *Revista brasileira de enfermagem* 72(1), pp. 231–240. doi: 10.1590/0034-7167-2017-0730.

Asselin, M.E. 2003. Insider Research: Issues to Consider When Doing Qualitative Research in Your Own Setting. *Journal for Nurses in Professional Development* 19(2). Available at: [https://journals.lww.com/jnsdonline/Fulltext/2003/03000/Insider\\_Research\\_\\_Issues\\_to\\_Consider\\_When\\_Doing.8.aspx](https://journals.lww.com/jnsdonline/Fulltext/2003/03000/Insider_Research__Issues_to_Consider_When_Doing.8.aspx).

Awasthi, S. et al. 2019. Optimizing Time to Treatment to Achieve Durable Biochemical Disease Control after Surgery in Prostate Cancer: A Multi-Institutional Cohort Study. *Cancer Epidemiology, Biomarkers & Prevention* 28(3), pp. 570–577. doi: 10.1158/1055-9965.EPI-18-0812.

Azungah, T. 2018. Qualitative research: deductive and inductive approaches to data analysis. *Qualitative Research Journal* 18(4), pp. 383–400. doi: 10.1108/QRJ-D-18-00035.

Azzopardi, J., Gauci, D., Parker, P.A., Calleja, N., Sloan, J.A. and Zammit, R. 2017. Breaking bad news in cancer: an assessment of Maltese patients' preferences.

Badr, H. 2022. Couple Relationships and Cancer. In: *Psychological Aspects of Cancer*. Springer, pp. 41–51.

Badr, H. and Acitelli, L.K. 2017. Re-thinking dyadic coping in the context of chronic illness. *Current opinion in psychology* 13, pp. 44–48. doi: 10.1016/j.copsyc.2016.03.001.

## References

- Badr, H. and Taylor, C.L.C. 2009. Sexual dysfunction and spousal communication in couples coping with prostate cancer. *Psycho-oncology* 18(7), pp. 735–746. doi: 10.1002/pon.1449.
- Baez, B. 2002. Confidentiality in qualitative research: Reflections on secrets, power and agency. *Qualitative Research - QUAL RES* 2, pp. 35–58. doi: 10.1177/1468794102002001638.
- Baldacchino, D.R. 2006. Nursing competencies for spiritual care. *Journal of Clinical Nursing* 15(7), pp. 885–896. doi: JCN1643 [pii].
- Baldacchino, D.R., Borg, J., Muscat, C. and Sturgeon, C. 2012. Psychology and theology meet: illness appraisal and spiritual coping. *Western journal of nursing research* 34(6), pp. 818–847. doi: 10.1177/0193945912441265.
- Baltes, P.B. 1987. Theoretical propositions of life-span developmental psychology: On the dynamics between growth and decline. *Developmental Psychology* 23, pp. 611–626. doi: 10.1037/0012-1649.23.5.611.
- Bamidele, O., McGarvey, H., Lagan, B.M., Parahoo, K., Chinegwundoh MBE, F. and McCaughan, E. 2019. “Man in the driving seat”: A grounded theory study of the psychosocial experiences of Black African and Black Caribbean men treated for prostate cancer and their partners. *Psycho-Oncology* 28(8), pp. 1712–1720. doi: 10.1002/pon.5150.
- Bartolo, M. 2022. Why is sex still a taboo in Malta?.
- Becerra Pérez, M.M., Menear, M., Brehaut, J.C. and Légaré, F. 2016. Extent and Predictors of Decision Regret about Health Care Decisions: A Systematic Review. *Medical Decision Making* 36(6), pp. 777–790. doi: 10.1177/0272989X16636113.
- Beck, A.M., Robinson, J.W. and Carlson, L.E. 2013. Sexual values as the key to maintaining satisfying sex after prostate cancer treatment: The physical pleasure–relational intimacy model of sexual motivation. *Archives of Sexual Behavior* 42(8), pp. 1637–1647. doi: 10.1007/s10508-013-0168-z.
- Beebe, L.H. 2007. What Can We Learn From Pilot Studies? *Perspectives in Psychiatric Care* 43(4), pp. 213–218. doi: 10.1111/j.1744-6163.2007.00136.x.
- Berg, C.A. and Upchurch, R. 2007. A developmental-contextual model of couples coping with chronic illness across the adult life span. *Psychological Bulletin* 133(6), pp. 920–954. doi: 10.1037/0033-2909.133.6.920.

## References

- Berg, C.A. et al. 2008. Collaborative coping and daily mood in couples dealing with prostate cancer. *Psychology and Aging* 23(3), pp. 505–516.
- Berg, C.A., Wiebe, D.J. and Butner, J. 2011. Affect covariation in marital couples dealing with stressors surrounding prostate cancer. *Gerontology* 57(2), pp. 167–172. doi: 10.1159/000318642.
- Berger, R. 2015. Now I see it, now I don't: researcher's position and reflexivity in qualitative research. *Qualitative Research* 15(2), pp. 219–234. doi: 10.1177/1468794112468475.
- van den Bergh, R.C.N., Albertsen, P.C., Bangma, C.H., Freedland, S.J., Graefen, M., Vickers, A. and van der Poel, H.G. 2013. Timing of Curative Treatment for Prostate Cancer: A Systematic Review. *European Urology* 64(2), pp. 204–215. doi: 10.1016/j.eururo.2013.02.024.
- Bestmann, B., Loetters, C., Diemer, T., Weidner, W., Kuchler, T. and Rohde, V. 2007. Prostate-specific symptoms of prostate cancer in a German general population. *Prostate cancer and prostatic diseases* 10(1), pp. 52–59. doi: 10.1038/sj.pcan.4500921.
- Bird, C. 2005. How I Stopped Dreading and Learned to Love Transcription. *Qualitative Inquiry* 11, pp. 226–248. doi: 10.1177/1077800404273413.
- Bodenmann 2005a. *Couples coping with stress: Emerging perspectives on dyadic coping*. Washington, DC, US: American Psychological Association. doi: 10.1037/11031-000.
- Bodenmann, G. 2005b. Dyadic Coping and Its Significance for Marital Functioning. *Couples Coping with Stress: Emerging Perspectives on Dyadic Coping* . doi: 10.1037/11031-002.
- Bolger, N., Zuckerman, A. and Kessler, R.C. 2000. Invisible support and adjustment to stress. *Journal of Personality and Social Psychology* 79(6), pp. 953–961. doi: 10.1037/0022-3514.79.6.953.
- Bonner, A. and Tolhurst, G. 2002. Insider-outsider perspectives of participant observation. *Nurse researcher* 9, pp. 7–19. doi: 10.7748/nr2002.07.9.4.7.c6194.
- Bowie, J., Brunckhorst, O., Stewart, R., Dasgupta, P. and Ahmed, K. 2021. Body image, self-esteem, and sense of masculinity in patients with prostate cancer: a qualitative meta-synthesis. *Journal of Cancer Survivorship* . Available at: <https://doi.org/10.1007/s11764-021-01007-9>.

## References

- Boyatzis, R.E. 1998. Transforming qualitative information: Thematic analysis and code development. *Transforming qualitative information: Thematic analysis and code development.* , pp. xvi, 184–xvi, 184.
- Bradshaw, C., Atkinson, S. and Doody, O. 2017. Employing a Qualitative Description Approach in Health Care Research. *Global Qualitative Nursing Research* 4, p. 2333393617742282. doi: 10.1177/2333393617742282.
- Braide, K., Kindblom, J., Lindencrona, U., Månsson, M. and Hugosson, J. 2019. The value of a bladder-filling protocol for patients with prostate cancer who receive post-operative radiation: results from a prospective clinical trial. *Acta oncologica (Stockholm, Sweden)* 58(4), pp. 463–468. doi: 10.1080/0284186X.2018.1554261.
- Brannick, T. and Coghlan, D. 2007. In Defense of Being “Native”: The Case for Insider Academic Research. *Organizational Research Methods* 10(1), pp. 59–74. doi: 10.1177/1094428106289253.
- Braun, V. and Clarke, V. 2006. Using thematic analysis in psychology. *Qualitative Research in Psychology* 3(2), pp. 77–101. doi: 10.1191/1478088706qp063oa.
- Braun, V. and Clarke, V. 2019. Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health* 11(4), pp. 589–597. doi: 10.1080/2159676X.2019.1628806.
- Braun, V. and Clarke, V. 2021. To saturate or not to saturate? Questioning data saturation as a useful concept for thematic analysis and sample-size rationales. *Qualitative Research in Sport, Exercise and Health* 13(2), pp. 201–216. doi: 10.1080/2159676X.2019.1704846.
- Bray, F., Ferlay, J., Soerjomataram, I., Siegel, R.L., Torre, L.A. and Jemal, A. 2018. Global cancer statistics 2018: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. *CA: A Cancer Journal for Clinicians* 68(6), pp. 394–424. doi: 10.3322/caac.21492.
- Brierley, J.D., Gospodarowicz, M.K. and Wittekind, C. 2017. *TNM Classification of Malignant Tumours*. Wiley. Available at: <https://books.google.com.mt/books?id=642GDQAAQBAJ>.
- Briguglio, M. and Tedesco, C. 2016. Social interaction of cancer survivors in Malta : a sociological analysis.
- Bruce, M.A., Bowie, J.V., Barge, H., Beech, B.M., LaVeist, T.A., Howard, D.L. and Thorpe, R.J. 2020. Religious Coping and Quality of Life Among Black and White Men With Prostate Cancer. *Cancer*

## References

*Control* 27(3), p. 1073274820936288. doi: 10.1177/1073274820936288.

Brüggemann, J. 2020. Redefining masculinity – Men's repair work in the aftermath of prostate cancer treatment. *Health Sociology Review*, pp. 1–14. doi: 10.1080/14461242.2020.1820367.

Caelli, K., Ray, L. and Mill, J. 2003. 'Clear as Mud': Toward Greater Clarity in Generic Qualitative Research. *International Journal of Qualitative Methods* 2(2), pp. 1–13. doi: 10.1177/160940690300200201.

Calasanti, T. 2016. Combating Ageism: How Successful Is Successful Aging? *The Gerontologist* 56(6), pp. 1093–1101. doi: 10.1093/geront/gnv076.

Calasanti, T. and Bowen, M.E. 2006. Spousal caregiving and crossing gender boundaries: Maintaining gendered identities. *Journal of Aging Studies* 20(3), pp. 253–263. doi: 10.1016/j.jaging.2005.08.001.

Cancer Research UK 2021. Prostate cancer treatment statistics. Available at: <https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/prostate-cancer/diagnosis-and-treatment#heading-Zero> [Accessed: 27 July 2022].

Carey, J.W. 1989. *Communication as Culture: Essays on Media and Society*. Unwin Hyman. Available at: <https://books.google.com.mt/books?id=1XWzQgAACAAJ>.

Carioli, G., Bertuccio, P., Boffetta, P., Levi, F., La Vecchia, C., Negri, E. and Malvezzi, M. 2020. European cancer mortality predictions for the year 2020 with a focus on prostate cancer. *Annals of oncology: official journal of the European Society for Medical Oncology* 31(5), pp. 650–658. doi: 10.1016/j.annonc.2020.02.009.

Carmona, C., Crutwell, J., Burnham, M. and Polak, L. 2021. Shared decision-making: summary of NICE guidance. *BMJ (Clinical research ed.)* 373, p. n1430. doi: 10.1136/bmj.n1430.

Carroll, C., Booth, A. and Lloyd-Jones, M. 2012. Should We Exclude Inadequately Reported Studies From Qualitative Systematic Reviews? An Evaluation of Sensitivity Analyses in Two Case Study Reviews. *Qualitative Health Research* 22(10), pp. 1425–1434. doi: 10.1177/1049732312452937.

Cella, D.F. et al. 1993. The Functional Assessment of Cancer Therapy scale: development and validation of the general measure. *Journal of clinical oncology: official journal of the American Society of Clinical Oncology* 11(3), pp. 570–579.



## References

Chambers, S.K. et al. 2013. Couple distress after localised prostate cancer. *Supportive Care in Cancer: Official Journal of the Multinational Association of Supportive Care in Cancer* 21(11), pp. 2967–2976. doi: 10.1007/s00520-013-1868-6.

Chambers, S.K. et al. 2018. Experiences of Australian men diagnosed with advanced prostate cancer: a qualitative study. *BMJ Open* 8(2), p. e019917. doi: 10.1136/bmjopen-2017-019917.

Chambers, S.K., Chung, E., Wittert, G. and Hyde, M.K. 2017. Erectile dysfunction, masculinity, and psychosocial outcomes: a review of the experiences of men after prostate cancer treatment. *Translational andrology and urology* 6(1), pp. 60–68. doi: 10.21037/tau.2016.08.12.

Chambers, S.K., Lowe, A., Hyde, M.K., Zajdlewicz, L., Gardiner, R.A., Sandoe, D. and Dunn, J. 2015. Defining young in the context of prostate cancer. *American journal of men's health* 9(2), pp. 103–114. doi: 10.1177/1557988314529991.

Chan, V.W.-S. et al. 2021. Effects of Delayed Radical Prostatectomy and Active Surveillance on Localised Prostate Cancer-A Systematic Review and Meta-Analysis. *Cancers* 13(13), p. 3274. doi: 10.3390/cancers13133274.

Charmaz, K. 2001. *Handbook of Interview Research*. SAGE Publications, Inc. Available at: <https://methods.sagepub.com/book/handbook-of-interview-research>.

Charmaz, K. 2014. *Constructing Grounded Theory*. SAGE Publications. Available at: [https://books.google.com.mt/books?id=v\\_GGAwAAQBAJ](https://books.google.com.mt/books?id=v_GGAwAAQBAJ).

Chatterjee, P. 2019. Discussion About Sexual Health: Is It Age Inappropriate? In: Chatterjee, P. ed. *Health and Wellbeing in Late Life: Perspectives and Narratives from India*. Singapore: Springer Singapore, pp. 129–146. Available at: [https://doi.org/10.1007/978-981-13-8938-2\\_8](https://doi.org/10.1007/978-981-13-8938-2_8).

Chen, H.-H., Lin, K.-S., Lin, P.-T., Kuo, L.-T., Fang, C.-C. and Chi, C.-C. 2020. Bladder volume reproducibility after water consumption in patients with prostate cancer undergoing radiotherapy: A systematic review and meta-analysis. *Biomedical Journal*. Available at: <https://www.sciencedirect.com/science/article/pii/S2319417020302018>.

Chetiyawardana, G., Hoskin, P.J. and Tsang, Y.M. 2020. The implementation of an empty bladder filling protocol for localised prostate volumetric modulated arctherapy (VMAT): early results of a single institution service evaluation. *The British Journal of Radiology* 93(1114), p. 20200548. doi: 10.1259/bjr.20200548.

## References

- Chien, C.-H., Chuang, C.-K., Liu, K.-L., Pang, S.-T., Wu, C.-T. and Chang, Y.-H. 2019. Prostate cancer-specific anxiety and the resulting health-related quality of life in couples. *Journal of advanced nursing* 75(1), pp. 63–74. doi: 10.1111/jan.13828.
- Clark, J.A., Bokhour, B.G., Inui, T.S., Silliman, R.A. and Talcott, J.A. 2003. Measuring patients' perceptions of the outcomes of treatment for early prostate cancer. *Medical care* 41(8), pp. 923–936. doi: 10.1097/00005650-200308000-00006.
- Cochrane, A., Woods, S., Dunne, S. and Gallagher, P. 2022. Unmet supportive care needs associated with quality of life for people with lung cancer: A systematic review of the evidence 2007–2020. *European Journal of Cancer Care* 31(1), p. e13525. doi: 10.1111/ecc.13525.
- Collaco, N. et al. 2018. Prostate cancer and the impact on couples: a qualitative metasynthesis. *Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer* 26(6), pp. 1703–1713. doi: 10.1007/s00520-018-4134-0.
- Collaço, N., Wagland, R., Alexis, O., Gavin, A., Glaser, A. and Watson, E.K. 2021. The experiences and needs of couples affected by prostate cancer aged 65 and under: a qualitative study. *Journal of cancer survivorship: research and practice* 15(2), pp. 358–366. doi: 10.1007/s11764-020-00936-1.
- Connell, R.W. 1995. *Masculinities*. University of California Press. Available at: <https://books.google.com.mt/books?id=44JHYPOy8aEC>.
- Connell, R.W. and Messerschmidt, J.W. 2005. Hegemonic Masculinity: Rethinking the Concept. *Gender & Society* 19(6), pp. 829–859. doi: 10.1177/0891243205278639.
- Cooperberg, M.R., Pasta, D.J., Elkin, E.P., Litwin, M.S., Latini, D.M., Du Chane, J. and Carroll, P.R. 2005. The University of California, San Francisco Cancer of the Prostate Risk Assessment score: a straightforward and reliable preoperative predictor of disease recurrence after radical prostatectomy. *The Journal of urology* 173(6), pp. 1938–1942. doi: 10.1097/01.ju.0000158155.33890.e7.
- Corden, A. and Sainsbury, R. 2006. Using Verbatim Quotations in Reporting Qualitative Social Research: The views of research users.
- Couët, N. et al. 2015. Assessments of the extent to which health-care providers involve patients in decision making: a systematic review of studies using the OPTION instrument. *Health Expectations* 18(4), pp. 542–561. doi: 10.1111/hex.12054.

## References

Couper, J.W., Bloch, S., Love, A., Duchesne, G., Macvean, M. and Kissane, D.W. 2006. The psychosocial impact of prostate cancer on patients and their partners. *The Medical journal of Australia* 185(8), p. 428.

Covvey, J.R. et al. 2019. Barriers and facilitators to shared decision-making in oncology: a systematic review of the literature. *Supportive Care in Cancer* 27(5), pp. 1613–1637. doi: 10.1007/s00520-019-04675-7.

Coyne, J.C. and Smith, D.A. 1991. Couples coping with a myocardial infarction: a contextual perspective on wives' distress. *Journal of personality and social psychology* 61(3), pp. 404–412. doi: 10.1037//0022-3514.61.3.404.

Crawford, E.D. et al. 2019. Androgen-targeted therapy in men with prostate cancer: evolving practice and future considerations. *Prostate Cancer and Prostatic Diseases* 22(1), pp. 24–38. doi: 10.1038/s41391-018-0079-0.

Creswell, J.W. 2012. *Qualitative Inquiry and Research Design: Choosing Among Five Approaches*. SAGE Publications. Available at: <https://books.google.com.mt/books?id=OJYEbDtkxq8C>.

Creswell, J.W. and Poth, C.N. 2017. *Qualitative Inquiry and Research Design (international Student Edition): Choosing Among Five Approaches*. Sage Publications.

Critical Appraisal Skills Programme 2019. Critical Appraisal Skills Programme. CASP qualitative checklist, <https://casp-uk.net/wp-content/uploads/2018/01/CASP-Qualitative-Checklist-2018.pdf>. Available at: <https://casp-uk.net/wp-content/uploads/2018/01/CASP-Qualitative-Checklist-2018.pdf> [Accessed: 19 October 2021].

Cuyppers, M., Lamers, R.E.D., de Vries, M., Husson, O., Kil, P.J.M. and van de Poll-Franse, L.V. 2016. Prostate cancer survivors with a passive role preference in treatment decision-making are less satisfied with information received: Results from the PROFILES registry. *Urologic oncology* 34(11), p. 482.e11-482.e18. doi: 10.1016/j.urolonc.2016.06.015.

Dash, S., Shakyawar, S.K., Sharma, M. and Kaushik, S. 2019. Big data in healthcare: management, analysis and future prospects. *Journal of Big Data* 6(1), p. 54. doi: 10.1186/s40537-019-0217-0.

Data Protection Act [UK] 2018. *General Data Protection Act*. Available at: <https://www.gov.uk/government/collections/data-protection-act-2018> [Accessed: 20 June 2020].

## References

- Dein, S. 2004. Explanatory models of and attitudes towards cancer in different cultures. *The Lancet Oncology* 5(2), pp. 119–124. doi: [//doi.org/10.1016/S1470-2045\(04\)01386-5](https://doi.org/10.1016/S1470-2045(04)01386-5).
- De Nunzio, C. et al. 2019. The EORTC quality of life questionnaire predicts early and long-term incontinence in patients treated with robotic assisted radical prostatectomy: Analysis of a large single center cohort. *Urologic oncology* 37(12), pp. 1006–1013. doi: [10.1016/j.urolonc.2019.06.024](https://doi.org/10.1016/j.urolonc.2019.06.024).
- DeJonckheere, M. and Vaughn, L.M. 2019. Semistructured interviewing in primary care research: a balance of relationship and rigour. *Family Medicine and Community Health* 7(2), p. e000057. doi: [10.1136/fmch-2018-000057](https://doi.org/10.1136/fmch-2018-000057).
- Denscombe, M. 2017. *EBOOK: The Good Research Guide: For Small-Scale Social Research Projects*. McGraw-Hill Education. Available at: <https://books.google.com.mt/books?id=SMovEAAAQBAJ>.
- Denzin, N.K. and Lincoln, Y.S. 2005. *The SAGE Handbook of Qualitative Research*. Sage Publications. Available at: <https://books.google.com.mt/books?id=X85J8ipMpZEC>.
- Denzin, N.K. and Lincoln, Y.S. 2017. *The SAGE Handbook of Qualitative Research*. SAGE Publications. Available at: <https://books.google.com.mt/books?id=l35ZDwAAQBAJ>.
- Department of Social Security [Malta] 2022. Retirement Pension. Available at: <https://socialsecurity.gov.mt/en/information-and-applications-for-benefits-and-services/contributory-pensions/retirement-pension/> [Accessed: 7 November 2022].
- Dickson-Swift, V., James, E.L., Kippen, S. and Liamputtong, P. 2007. Doing sensitive research: what challenges do qualitative researchers face? *Qualitative Research* 7(3), pp. 327–353. doi: [10.1177/1468794107078515](https://doi.org/10.1177/1468794107078515).
- Din, I. and Cullingford, C. 2004. Boyzone and Bhangra: the place of popular and minority cultures. *Race Ethnicity and Education* 7(3), pp. 307–320. doi: [10.1080/1361332042000257083](https://doi.org/10.1080/1361332042000257083).
- Donovan, K.A., Walker, L.M., Wassersug, R.J., Thompson, L.M.A. and Robinson, J.W. 2015. Psychological effects of androgen-deprivation therapy on men with prostate cancer and their partners. *Cancer (0008543X)* 121(24), pp. 4286–4299. doi: [10.1002/cncr.29672](https://doi.org/10.1002/cncr.29672).
- Downing, A. et al. 2016. Life after prostate cancer diagnosis: protocol for a UK-wide patient-reported outcomes study. *BMJ Open* 6(12), p. e013555. doi: [10.1136/bmjopen-2016-013555](https://doi.org/10.1136/bmjopen-2016-013555).

## References

Doyle, L., McCabe, C., Keogh, B., Brady, A. and McCann, M. 2020. An overview of the qualitative descriptive design within nursing research. *Journal of research in nursing : JRN* 25(5), pp. 443–455. doi: 10.1177/1744987119880234.

Dunlop, A. et al. 2020. Daily adaptive radiotherapy for patients with prostate cancer using a high field MR-linac: Initial clinical experiences and assessment of delivered doses compared to a C-arm linac. *Clinical and Translational Radiation Oncology* 23, pp. 35–42. doi: 10.1016/j.ctro.2020.04.011.

Dwyer, S.C. and Buckle, J.L. 2009. The Space Between: On Being an Insider-Outsider in Qualitative Research. *International Journal of Qualitative Methods* 8(1), pp. 54–63. doi: 10.1177/160940690900800105.

Eisemann, N., Waldmann, A., Rohde, V. and Katalinic, A. 2014. Quality of life in partners of patients with localised prostate cancer. *Quality of life research: an international journal of quality of life aspects of treatment, care and rehabilitation* 23(5), pp. 1557–1568. doi: 10.1007/s11136-013-0588-1.

Eisikovits, Z. and Koren, C. 2010. Approaches to and Outcomes of Dyadic Interview Analysis. *Qualitative health research* 20, pp. 1642–55. doi: 10.1177/1049732310376520.

Elliott, K. 2016. Caring Masculinities: Theorizing an Emerging Concept. *Men and Masculinities* 19(3), pp. 240–259. doi: 10.1177/1097184X15576203.

Elliott (nee Murray), K.-E.J., Scott, J.L., Monsour, M. and Nuwayhid, F. 2015. Profiles of dyadic adjustment for advanced prostate cancer to inform couple-based intervention. *Psychology & Health* 30(11), pp. 1259–1273. doi: 10.1080/08870446.2015.1043301.

Ellis, C. 1995. EMOTIONAL AND ETHICAL QUAGMIRES IN RETURNING TO THE FIELD. *Journal of Contemporary Ethnography* 24(1), pp. 68–98. doi: 10.1177/089124195024001003.

Emslie, C., Browne, S., MacLeod, U., Rozmovits, L., Mitchell, E. and Ziebland, S. 2009. 'Getting through' not 'going under': A qualitative study of gender and spousal support after diagnosis with colorectal cancer. *Social Science & Medicine* 68(6), pp. 1169–1175. doi: 10.1016/j.socscimed.2009.01.004.

Epstein, J.I., Egevad, L., Amin, M.B., Delahunt, B., Srigley, J.R. and Humphrey, P.A. 2016. The 2014 International Society of Urological Pathology (ISUP) Consensus Conference on Gleason Grading of Prostatic Carcinoma: Definition of Grading Patterns and Proposal for

## References

a New Grading System. *The American journal of surgical pathology* 40(2), pp. 244–252. doi: 10.1097/PAS.0000000000000530.

Ervik, B., Nordøy, T. and Asplund, K. 2013. In the middle and on the sideline: the experience of spouses of men with prostate cancer. *Cancer nursing* 36(3), pp. E7–E14. doi: 10.1097/NCC.0b013e31824fe1ef.

Ettridge, K.A. et al. 2018. 'Prostate cancer is far more hidden...': Perceptions of stigma, social isolation and help-seeking among men with prostate cancer. *European journal of cancer care* 27(2), p. e12790. doi: 10.1111/ecc.12790.

European Commission 2016. EU General Data Protection Regulation (GDPR): Regulation (EU) 2016/679. Available at: <https://gdpr-info.eu/>.

European Commission 2019. *Special Barometer 493*. Available at: <https://europa.eu/eurobarometer/surveys/detail/2251>.

European Commission 2020. European Health Union - Protecting the health of Europeans and collectively responding to cross-border health crises. Available at: [https://ec.europa.eu/info/strategy/priorities-2019-2024/promoting-our-european-way-of-life/european-health-union\\_en#documents](https://ec.europa.eu/info/strategy/priorities-2019-2024/promoting-our-european-way-of-life/european-health-union_en#documents).

European Commission 2022. Country profile, Malta. Available at: [https://european-union.europa.eu/principles-countries-history/country-profiles/malta\\_en](https://european-union.europa.eu/principles-countries-history/country-profiles/malta_en) [Accessed: 5 July 2022].

European Union 2021. Europe's Beating Cancer Plan. Available at: [https://ec.europa.eu/health/system/files/2022-02/eu\\_cancer-plan\\_en\\_0.pdf](https://ec.europa.eu/health/system/files/2022-02/eu_cancer-plan_en_0.pdf) [Accessed: 23 June 2022].

Ezer, H., Chachamovich, J.L.R. and Chachamovich, E. 2011. Do men and their wives see it the same way? Congruence within couples during the first year of prostate cancer. *Psycho-Oncology* 20(2), pp. 155–164. doi: 10.1002/pon.1724.

Eziefula, C.U., Grunfeld, E.A. and Hunter, M.S. 2013. 'You know I've joined your club... I'm the hot flush boy': a qualitative exploration of hot flushes and night sweats in men undergoing androgen deprivation therapy for prostate cancer. *Psycho-oncology* 22(12), pp. 2823–2830. doi: 10.1002/pon.3355.

Fagundes, C.P., Berg, C.A. and Wiebe, D.J. 2012. Intrusion, avoidance, and daily negative affect among couples coping with prostate cancer: A dyadic investigation. *Journal of Family Psychology* 26(2), pp. 246–253.

## References

Falconier, M.K., Jackson, J.B., Hilpert, P. and Bodenmann, G. 2015. Dyadic coping and relationship satisfaction: A meta-analysis. *Clinical Psychology Review* 42, pp. 28–46. doi: 10.1016/j.cpr.2015.07.002.

Feldman, M.S. et al. 2003. *Gaining Access: A Practical and Theoretical Guide for Qualitative Researchers*. AltaMira Press. Available at: <https://books.google.com.mt/books?id=gT99QgAACAAJ>.

Feldman-Stewart, D. et al. 2010. Information needs of early-stage prostate cancer patients: A comparison of nine countries. *Radiotherapy and Oncology* 94(3), pp. 328–333. doi: 10.1016/j.radonc.2009.12.038.

Fergus, K.D. 2011. The rupture and repair of the couple's communal body with prostate cancer. *Families, Systems & Health: The Journal of Collaborative Family HealthCare* 29(2), pp. 95–113. doi: 10.1037/a0023413.

Ferlay, J., Colombet, M., Soerjomataram, I., Parkin, D.M., Piñeros, M., Znaor, A. and Bray, F. 2021. Cancer statistics for the year 2020: An overview. *International Journal of Cancer* 149(4), pp. 778–789. doi: 10.1002/ijc.33588.

Fillion, L., de Serres, M., Cook, S., Goupil, R.L., Bairati, I. and Doll, R. 2009. Professional Patient Navigation in Head and Neck Cancer. *Head and Neck Cancer* 25(3), pp. 212–221. doi: 10.1016/j.soncn.2009.05.004.

Fiorillo, D. and Sabatini, F. 2015. Structural social capital and health in Italy. *Economics & Human Biology* 17, pp. 129–142. doi: 10.1016/j.ehb.2015.02.004.

Fontana, A. and Frey, J.H. 2005. The Interview: From Neutral Stance to Political Involvement. *The Sage handbook of qualitative research*, 3rd ed. , pp. 695–727.

Forbat, L., White, I., Marshall-Lucette, S. and Kelly, D. 2012. Discussing the sexual consequences of treatment in radiotherapy and urology consultations with couples affected by prostate cancer. *BJU International* 109(1), pp. 98–103. doi: 10.1111/j.1464-410X.2011.10257.x.

Frankland, J. et al. 2019. Follow-up care after treatment for prostate cancer: evaluation of a supported self-management and remote surveillance programme. *BMC Cancer* 19(1), p. 368. doi: 10.1186/s12885-019-5561-0.

Franzel, B., Schwiegershausen, M., Heusser, P. and Berger, B. 2013. How to locate and appraise qualitative research in complementary and

## References

alternative medicine. *BMC Complementary and Alternative Medicine* 13(1), p. 125. doi: 10.1186/1472-6882-13-125.

Frederickson, K., Rivas Acuña, V., Whetsell, M. and Tallier, P. 2005. Cross-cultural analysis for conceptual understanding: English and Spanish perspectives. *Nursing science quarterly* 18(4), pp. 286–292. doi: 10.1177/0894318405280380.

Frey, A., Pedersen, C., Lindberg, H., Bisbjerg, R., Sønksen, J. and Fode, M. 2017. Prevalence and Predicting Factors for Commonly Neglected Sexual Side Effects to External-Beam Radiation Therapy for Prostate Cancer. *The Journal of Sexual Medicine* 14(4), pp. 558–565. doi: 10.1016/j.jsxm.2017.01.015.

Galbraith, M.E., Pedro, L.W., Jaffe, A.R. and Allen, T.L. 2008. Describing health-related outcomes for couples experiencing prostate cancer: differences and similarities. *Oncology nursing forum* 35(5), p. 794.

Galbraith, M.E., Fink, R. and Wilkins, G.G. 2011. Couples Surviving Prostate Cancer: Challenges in Their Lives and Relationships. *Seminars in Oncology Nursing* 27(4), pp. 300–308. doi: 10.1016/j.soncn.2011.07.008.

Gallagher, M.W., Long, L.J., Richardson, A. and D'Souza, J.M. 2019. Resilience and Coping in Cancer Survivors: The Unique Effects of Optimism and Mastery. *Cognitive Therapy and Research* 43(1), pp. 32–44. doi: 10.1007/s10608-018-9975-9.

Garos, S., Kluck, A. and Aronoff, D. 2007. Prostate cancer patients and their partners: differences in satisfaction indices and psychological variables. *The journal of sexual medicine* 4(5), pp. 1394–1403. doi: 10.1111/j.1743-6109.2007.00545.x.

Gil, E.F. and Bob, S. 1999. Culturally competent research: an ethical perspective. *Clinical psychology review* 19(1), pp. 45–55. doi: 10.1016/s0272-7358(98)00019-1.

Goldsmith, D.J. 2009. Uncertainty and communication in couples coping with serious illness. *Uncertainty, information management, and disclosure decisions: Theories and applications.* , pp. 203–225.

Gotay, C.C., Blaine, D., Haynes, S.N., Holup, J. and Pagano, I.S. 2002. Assessment of quality of life in a multicultural cancer patient population. *Psychological Assessment* 14(4), pp. 439–450. doi: 10.1037/1040-3590.14.4.439.

Grafanaki, S. 1996. How research can change the researcher: The need for sensitivity, flexibility and ethical boundaries in conducting qualitative research in counselling/psychotherapy. *British Journal of*



## References

*Guidance & Counselling* 24(3), pp. 329–338. doi: 10.1080/03069889608253017.

Gray, R.E., Fitch, M., Phillips, C., Labrecque, M. and Fergus, K. 2000. To tell or not to tell: patterns of disclosure among men with prostate cancer. *Psycho-oncology* 9(4), pp. 273–282. doi: 10.1002/1099-1611(200007/08)9:4<273::aid-pon463>3.0.co;2-f.

Grech, D. 2018. Cancer survivors 'afraid to talk about emotions'. Available at: <https://timesofmalta.com/articles/view/cancer-survivors-afraid-to-talk-about-emotions.681338>.

Green, A., Winter, N., DiGiacomo, M., Oliffe, J.L., Ralph, N., Dunn, J. and Chambers, S.K. 2022. Experiences of female partners of prostate cancer survivors: A systematic review and thematic synthesis. *Health & Social Care in the Community* 30(4), pp. 1213–1232. doi: 10.1111/hsc.13644.

Griffith, R. and Tegnah, C. 2013. Maintaining professional boundaries: keep your distance. *British Journal of Community Nursing* 18(1), pp. 43–46. doi: 10.12968/bjcn.2013.18.1.43.

Grondhuis Palacios, L.A. et al. 2018. Suitable sexual health care according to men with prostate cancer and their partners. *Supportive care in cancer: official journal of the Multinational Association of Supportive Care in Cancer* 26(12), pp. 4169–4176. doi: 10.1007/s00520-018-4290-2.

Grün, A., Kawgan-Kagan, M., Kaul, D., Badakhshi, H., Stromberger, C., Budach, V. and Böhmer, D. 2019. Impact of bladder volume on acute genitourinary toxicity in intensity modulated radiotherapy for localized and locally advanced prostate cancer. *Strahlentherapie und Onkologie* 195(6), pp. 517–525. doi: 10.1007/s00066-018-1398-8.

Grunfeld, B., Drudge-Coates, L., Rixon, L., Eaton, E. and Cooper, A. 2013. 'The Only Way I Know How to Live Is to Work': A Qualitative Study of Work Following Treatment for Prostate Cancer. *Health psychology: official journal of the Division of Health Psychology, American Psychological Association* 32, pp. 75–82. doi: 10.1037/a0030387.

Guba, E.G. and Lincoln, Y.S. 2005. Paradigmatic Controversies, Contradictions, and Emerging Confluences. *The Sage handbook of qualitative research, 3rd ed.*, pp. 191–215.

Guercio, C. and Mehta, A. 2018. Predictors of Patient and Partner Satisfaction Following Radical Prostatectomy. *Sexual medicine reviews* 6(2), pp. 295–301. doi: 10.1016/j.sxmr.2017.08.005.

## References

Guo, Y. et al. 2019. Prognostic Significance of Young Age and Non-Bone Metastasis at Diagnosis in Patients with Metastatic Prostate Cancer: a SEER Population-Based Data Analysis. *Journal of Cancer* 10(3), pp. 556–567. doi: 10.7150/jca.29481.

Hakenberg, O.W. 2018. A brief overview of the development of robot-assisted radical prostatectomy. *Special issue on Robotics and Laparoscopy* 16(3), pp. 293–296. doi: 10.1016/j.aju.2018.06.006.

Hamilton, L.D., Dam, D.V. and Wassersug, R.J. 2016. The perspective of prostate cancer patients and patients' partners on the psychological burden of androgen deprivation and the dyadic adjustment of prostate cancer couples. *Psycho-Oncology* 25(7), pp. 823–831. doi: 10.1002/pon.3930.

Hammersley, M. and Traianou, A. 2014. Foucault and Research Ethics: On the Autonomy of the Researcher. *Qualitative Inquiry* 20(3), pp. 227–238. doi: 10.1177/1077800413489528.

Hanly, N., Mireskandari, S. and Juraskova, I. 2014. The struggle towards 'the New Normal': a qualitative insight into psychosexual adjustment to prostate cancer. *BMC urology* 14, p. 56. doi: 10.1186/1471-2490-14-56.

Hannes, K. and Macaitis, K. 2012. A move to more systematic and transparent approaches in qualitative evidence synthesis: update on a review of published papers. *Qualitative Research* 12(4), pp. 402–442. doi: 10.1177/1468794111432992.

Harden, J.K., Northouse, L.L. and Mood, D.W. 2006. Qualitative Analysis of Couples' Experience with Prostate Cancer by Age Cohort. *Cancer Nursing* 29(5), pp. 367–377. doi: 10.1097/00002820-200609000-00004.

Harding, J. 2013. *Qualitative Data Analysis from Start to Finish*. SAGE Publications. Available at: <https://books.google.com.mt/books?id=9YUQAgAAQBAJ>.

Harju, E., Rantanen, A., Helminen, M., Kaunonen, M., Isotalo, T. and Astedt-Kurki, P. 2018. Marital relationship and health-related quality of life of patients with prostate cancer and their spouses: A longitudinal clinical study. *Journal of clinical nursing* 27(13–14), pp. 2633–2639. doi: 10.1111/jocn.14343.

Heidegger, M. 1962. *Die Frage nach dem Ding: zu Kants Lehre von den transzendentalen Grundsätzen*.

Henry, P. 2015. Rigor in qualitative research: Promoting quality in social science research. *Res J Recent Sci ISSN 2277*, p. 2502.

## References

Hertz, R. 1995. Separate But Simultaneous Interviewing of Husbands and Wives: Making Sense of Their Stories. *Qualitative Inquiry* 1(4), pp. 429–451. doi: 10.1177/107780049500100404.

Hird, M. 2004. *Sex, Gender, and Science*. Palgrave Macmillan UK. Available at: [https://books.google.com.mt/books?id=hyJ\\_DAAAQBAJ](https://books.google.com.mt/books?id=hyJ_DAAAQBAJ).

Hodgkinson, K., Butow, P., Hunt, G.E., Pendlebury, S., Hobbs, K.M., Lo, S.K. and Wain, G. 2007. The development and evaluation of a measure to assess cancer survivors' unmet supportive care needs: the CaSUN (Cancer Survivors' Unmet Needs measure). *Psycho-Oncology* 16(9), pp. 796–804. doi: 10.1002/pon.1137.

Holloway, I. 1997. *Basic concepts for qualitative research*. Oxford: Blackwell Science.

Holmes-Rovner, M. et al. 2015. Informed Decision Making: Assessment of the Quality of Physician Communication about Prostate Cancer Diagnosis and Treatment. *Medical Decision Making* 35(8), pp. 999–1009. doi: 10.1177/0272989X15597226.

Horton, R.E. 2020. The implementation of prostate cancer information sessions to improve bowel and bladder preparation compliance. *Radiography* 26

Huff, A.S. 2008. *Designing Research for Publication*. SAGE Publications. Available at: <https://books.google.com.mt/books?id=Q7BDsZHYHywC>.

Hugosson, J. et al. 2019. A 16-yr Follow-up of the European Randomized study of Screening for Prostate Cancer. *European urology* 76(1), pp. 43–51. doi: 10.1016/j.eururo.2019.02.009.

Hunsley, J., Best, M., Lefebvre, M. and Vito, D. 2001. The Seven-Item Short Form of the Dyadic Adjustment Scale: Further Evidence for Construct Validity. *The American Journal of Family Therapy* 29(4), pp. 325–335. doi: 10.1080/01926180126501.

Husserl, E. 1970. *The crisis of European sciences and transcendental phenomenology: An introduction to phenomenological philosophy*. Northwestern University Press.

Husserl, E. 2001. *Logical Investigations Volume 1*.

Hyde, M.K. et al. 2017. Men's help-seeking in the first year after diagnosis of localised prostate cancer. *European journal of cancer care* 26(2). doi: 10.1111/ecc.12497.

## References

Hyde, M.K. et al. 2018. Predictors of long-term distress in female partners of men diagnosed with prostate cancer. *Psycho-Oncology* 27(3), pp. 946–954. doi: 10.1002/pon.4617.

Hynds, S. et al. 2011. Assessing the daily consistency of bladder filling using an ultrasonic Bladderscan device in men receiving radical conformal radiotherapy for prostate cancer. *The British journal of radiology* 84(1005), pp. 813–818. doi: 10.1259/bjr/50048151.

Ingrosso, G. et al. 2019. Interfraction prostate displacement during image-guided radiotherapy using intraprostatic fiducial markers and a cone-beam computed tomography system: A volumetric off-line analysis in relation to the variations of rectal and bladder volumes. *Journal of cancer research and therapeutics* 15(Supplement), pp. S69–S75. doi: 10.4103/jcrt.JCRT\_463\_17.

James, C., Brunckhorst, O., Eymech, O., Stewart, R., Dasgupta, P. and Ahmed, K. 2022. Fear of cancer recurrence and PSA anxiety in patients with prostate cancer: a systematic review. *Supportive Care in Cancer*. Available at: <https://doi.org/10.1007/s00520-022-06876-z>.

Jitender, S., Mahajan, R., Rathore, V. and Choudhary, R. 2018. Quality of life of cancer patients. *Journal of experimental therapeutics & oncology* 12(3), pp. 217–221.

Johnson, M.J., Huang, C., Chen, H., Jones, L. and Twiddy, M. 2021. Prostate cancer: unmet supportive and palliative care needs: national survey of patients and family carers. *BMJ Supportive & Palliative Care*, p. bmjspcare-2021-003438. doi: 10.1136/bmjspcare-2021-003438.

Jones, N. and Corrigan, P.W. 2014. Understanding stigma. The stigma of disease and disability: Understanding causes and overcoming injustices., pp. 9–34. doi: 10.1037/14297-002.

Josfeld, L., Keinki, C., Pammer, C., Zomorodbakhsch, B. and Hübner, J. 2021. Cancer patients' perspective on shared decision-making and decision aids in oncology. *Journal of Cancer Research and Clinical Oncology* 147(6), pp. 1725–1732. doi: 10.1007/s00432-021-03579-6.

Kallio, H., Pietila, A.-M., Johnson, M. and Kangasniemi, M. 2016. Systematic methodological review: developing a framework for a qualitative semi-structured interview guide. *Journal of advanced nursing* 72(12), pp. 2954–2965. doi: 10.1111/jan.13031.

Kalmijn, M. and Saraceno, C. 2008. A COMPARATIVE PERSPECTIVE ON INTERGENERATIONAL SUPPORT. *European Societies* 10(3), pp. 479–508. doi: 10.1080/14616690701744364.

## References

- Kanuha, V.K. 2000. 'Being' native versus 'going native': conducting social work research as an insider. *Social work* 45(5), pp. 439–447. doi: 10.1093/sw/45.5.439.
- Kaplowitz, M.D. 2000. *Statistical Analysis of Sensitive Topics in Group and Individual Interviews.*, p. 14.
- Karnieli-Miller, O., Strier, R. and Pessach, L. 2009. Power Relations in Qualitative Research. *Qualitative health research* 19, pp. 279–89. doi: 10.1177/1049732308329306.
- Kassianos, A.P., Raats, M.M. and Gage, H. 2016. An Exploratory Study on the Information Needs of Prostate Cancer Patients and Their Partners. *Health psychology research* 4(1), pp. 4786–4786. doi: 10.4081/hpr.2016.4786.
- Kazer, M.W., Harden, J., Burke, M., Sanda, M.G., Hardy, J., Bailey, D.E., and PROSTQA Study Group 2011. The experiences of unpartnered men with prostate cancer: a qualitative analysis. *Journal of cancer survivorship : research and practice* 5(2), pp. 132–141. doi: 10.1007/s11764-010-0157-3.
- Keller, J., Wiedemann, A.U., Hohl, D.H., Scholz, U., Burkert, S., Schrader, M. and Knoll, N. 2017. Predictors of dyadic planning: Perspectives of prostate cancer survivors and their partners. *British journal of health psychology* 22(1), pp. 42–59. doi: 10.1111/bjhp.12216.
- Kelly, D., Forbat, L., Marshall-Lucette, S. and White, I. 2015. Co-constructing sexual recovery after prostate cancer: a qualitative study with couples. *Translational andrology and urology* 4(2), pp. 131-138. doi: 10.3978/j.issn.2223-4683.2015.04.05.
- Kelly, D., Sakellariou, D., Fry, S. and Vougioukalou, S. 2018. Heteronormativity and prostate cancer: A discursive paper. *Journal of clinical nursing* 27(1–2), pp. 461–467. doi: 10.1111/jocn.13844.
- Kerleau, C. et al. 2016. Long-term quality of life among localised prostate cancer survivors: QALIPRO population-based study. *European Journal of Cancer* 63, pp. 143–153. doi: 10.1016/j.ejca.2016.05.020.
- Kershaw, T.S., Mood, D.W., Newth, G., Ronis, D.L., Sanda, M.G., Vaishampayan, U. and Northouse, L.L. 2008. Longitudinal analysis of a model to predict quality of life in prostate cancer patients and their spouses. *Annals of behavioral medicine : a publication of the Society of Behavioral Medicine* 36(2), pp. 117–128. doi: 10.1007/s12160-008-9058-3.

## References

Kilanowski, J.F. 2006. Lessons learned from a pilot study on the health status of children from itinerant populations. *Journal of pediatric health care : official publication of National Association of Pediatric Nurse Associates & Practitioners* 20(4), pp. 253–260. doi: 10.1016/j.pedhc.2005.12.018.

King, N. 2004. *Essential Guide to Qualitative Methods in Organizational Research*. London: SAGE Publications Ltd. Available at: <http://sk.sagepub.com/books/essential-guide-to-qualitative-methods-in-organizational-research>.

Kirkman, M., Young, K., Evans, S., Millar, J., Fisher, J., Mazza, D. and Ruseckaite, R. 2017. Men's perceptions of prostate cancer diagnosis and care: insights from qualitative interviews in Victoria, Australia. *BMC Cancer* 17(1), p. 704. doi: 10.1186/s12885-017-3699-1.

Knodel, J. 1995. Focus groups as a qualitative method for crosscultural research in social gerontology. *Journal of Cross-Cultural Gerontology* 10(1), pp. 7–20. doi: 10.1007/BF00972029.

Korotkin, B.D., Hoerger, M., Voorhees, S., Allen, C.O., Robinson, W.R. and Duberstein, P.R. 2019. Social support in cancer: How do patients want us to help? *Journal of Psychosocial Oncology* 37(6), pp. 699–712. doi: 10.1080/07347332.2019.1580331.

Krist, A.H., Tong, S.T., Aycok, R.A. and Longo, D.R. 2017. Engaging Patients in Decision-Making and Behavior Change to Promote Prevention. *Studies in health technology and informatics* 240, pp. 284–302.

Krusenvik, L. 2016. *Using Case Studies as a Scientific Method: Advantages and Disadvantages*.

Kurian, C.J., Leader, A.E., Thong, M.S.Y., Keith, S.W. and Zeigler-Johnson, C.M. 2018. Examining relationships between age at diagnosis and health-related quality of life outcomes in prostate cancer survivors. *BMC Public Health* 18(1), p. 1060. doi: 10.1186/s12889-018-5976-6.

Kuster, M., Backes, S., Brandstätter, V., Nussbeck, F.W., Bradbury, T.N., Sutter-Stickel, D. and Bodenmann, G. 2017. Approach-avoidance goals and relationship problems, communication of stress, and dyadic coping in couples. *Motivation and Emotion* 41(5), pp. 576–590. doi: 10.1007/s11031-017-9629-3.

Kvale, S. 1996. *Interviews: an introduction to qualitative research interviewing*. Sage Publications. Available at: <https://books.google.com.mt/books?id=tJPZAAAAMAAJ>.

## References

Kvale, S. 2007. Doing interviews. *Doing interviews.* , pp. xxi, 157–xxi, 157. doi: 10.4135/9781849208963.

Laine, M. de 2000. *Fieldwork, participation and practice : ethics and dilemmas in qualitative research / Marlene de Laine.* London ; Thousand Oaks, Calif: SAGE. Available at: <http://www.loc.gov/catdir/toc/fy022/00711565.html>.

Lancaster, G.A., Dodd, S. and Williamson, P.R. 2004. Design and analysis of pilot studies: recommendations for good practice. *Journal of evaluation in clinical practice* 10(2), pp. 307–312. doi: 10.1111/j..2002.384.doc.x.

Lapadat, J.C. and Lindsay, A.C. 1999. Transcription in Research and Practice: From Standardization of Technique to Interpretive Positionings. *Qualitative Inquiry* 5(1), pp. 64–86. doi: 10.1177/107780049900500104.

Lardas, M. et al. 2017. Quality of Life Outcomes after Primary Treatment for Clinically Localised Prostate Cancer: A Systematic Review. *European urology* 72(6), pp. 869–885. doi: 10.1016/j.eururo.2017.06.035.

Lawler, M. et al. 2021. The European Code of Cancer Practice. *Journal of cancer policy* 28, p. 100282. doi: 10.1016/j.jcpc.2021.100282.

Lazarus, R.S. and Folkman, S. 1984. *Stress, Appraisal, and Coping.* Springer Publishing Company. Available at: <https://books.google.com/mt/books?id=i-ySQQuUpr8C>.

Lehto, U.-S., Tenhola, H., Taari, K. and Aromaa, A. 2017. Patients' perceptions of the negative effects following different prostate cancer treatments and the impact on psychological well-being: a nationwide survey. *British Journal of Cancer* 116(7), pp. 864–873. doi: 10.1038/bjc.2017.30.

Levy, A. and Cartwright, T. 2015. Men's strategies for preserving emotional well-being in advanced prostate cancer: An interpretative phenomenological analysis. *Psychology & health* 30(10), pp. 1164–1182. doi: 10.1080/08870446.2015.1040016.

Liamputtong, P. 2022. *Researching the Vulnerable.* London. Available at: <https://methods.sagepub.com/book/researching-the-vulnerable>.

Lim, J., Paek, M. and Shon, E. 2015. Gender and role differences in couples' communication during cancer survivorship. *Cancer Nursing* 38(3), pp. E5–E60. doi: 10.1097/NCC.000000000000191.

## References

Lincoln, Y.S. and Guba, E.G. 1985. *Naturalistic Inquiry*. SAGE Publications. Available at: <https://books.google.com.mt/books?id=2oA9aWINEooC>.

Long, H.A., French, D.P. and Brooks, J.M. 2020. Optimising the value of the critical appraisal skills programme (CASP) tool for quality appraisal in qualitative evidence synthesis. *Research Methods in Medicine & Health Sciences* 1(1), pp. 31–42. doi: 10.1177/2632084320947559.

Long, K.M., McDermott, F. and Meadows, G.N. 2018. Being pragmatic about healthcare complexity: our experiences applying complexity theory and pragmatism to health services research. *BMC Medicine* 16(1), p. 94. doi: 10.1186/s12916-018-1087-6.

Long, H.A., French, D.P. and Brooks, J.M. 2020. Optimising the value of the critical appraisal skills programme (CASP) tool for quality appraisal in qualitative evidence synthesis. *Research Methods in Medicine & Health Sciences* 1(1), pp. 31–42. doi: 10.1177/2632084320947559.

Low, J. 2019. A Pragmatic Definition of the Concept of Theoretical Saturation. *Sociological Focus* 52(2), pp. 131–139. doi: 10.1080/00380237.2018.1544514.

Lyons, K.S. and Lee, C.S. 2020. The Association of Dyadic Symptom Appraisal With Physical and Mental Health Over Time in Care Dyads Living With Lung Cancer. *Journal of Family Nursing* 26(1), pp. 15–25. doi: 10.1177/1074840719889967.

Mallis, D., Moisidis, K., Kirana, P.S., Papaharitou, S., Simos, G. and Hatzichristou, D. 2006. Moderate and severe erectile dysfunction equally affects life satisfaction. *The journal of sexual medicine* 3(3), pp. 442–449. doi: S1743-6095(15)31331-X [pii].

Malta National Cancer Registry 2016. *Malta National Cancer Registry*.

Manne, S. and Badr, H. 2008. Intimacy and relationship processes in couples' psychosocial adaptation to cancer. *Cancer* 112(11 Suppl), pp. 2541–2555. doi: 10.1002/cncr.23450.

Manne, S., Badr, H., Zaider, T., Nelson, C. and Kissane, D. 2010. Cancer-related communication, relationship intimacy, and psychological distress among couples coping with localized prostate cancer. *Journal of Cancer Survivorship* 4(1), pp. 74–85. doi: 10.1007/s11764-009-0109-y.

Manne, S. et al. 2018. Interpersonal processes and intimacy among men with localized prostate cancer and their partners. *Journal of family psychology* : JFP : journal of the Division of Family Psychology of the



## References

American Psychological Association (Division 43) 32(5), pp. 664–675. doi: 10.1037/fam0000404.

Manne, S.L. et al. 2021. Relationship communication and the course of psychological outcomes among couples coping with localised prostate cancer. *European journal of cancer care* 30(4), p. e13401. doi: 10.1111/ecc.13401.

Manne, S.L., Ostroff, J.S., Norton, T.R., Fox, K., Goldstein, L. and Grana, G. 2006. Cancer-related relationship communication in couples coping with early stage breast cancer. *Psycho-Oncology* 15(3), pp. 234–247. doi: 10.1002/pon.941.

Manne, Zaider, T., Lee, D., Kissane, D., Kashy, D., Heckman, C. and Virtue, S.M. 2015. Holding back, intimacy, and psychological and relationship outcomes among couples coping with prostate cancer. *Journal of Family Psychology* 29(5), pp. 708–719. doi: 10.1037/fam0000096.

Marhold, M., Kramer, G., Krainer, M. and Le Magnen, C. 2022. The prostate cancer landscape in Europe: Current challenges, future opportunities. *Cancer Letters* 526, pp. 304–310. doi: 10.1016/j.canlet.2021.11.033.

Marshall, M.N. 1996. Sampling for qualitative research. *Family Practice* 13(6), pp. 522–526. doi: 10.1093/fampra/13.6.522.

Marshall, S.S., Haywood, K.L. and Fitzpatrick, R. 2005. *Patient Involvement and Collaboration in Shared Decision Making: A Structured Review to Inform Chronic Disease Management, Report from the Patient-Reported Health Instruments Group to the Department of Health*. Oxford, UK: National Centre for Health Outcomes Development.

Martínez-González, N.A., Plate, A., Markun, S., Senn, O., Rosemann, T. and Neuner-Jehle, S. 2019. Shared decision making for men facing prostate cancer treatment: a systematic review of randomized controlled trials. *Patient preference and adherence* 13, pp. 1153–1174. doi: 10.2147/PPA.S202034.

Mason, J. 2002. *Qualitative Researching*. SAGE Publications. Available at: <https://books.google.com.mt/books?id=gW5su96QHL0C>.

Maxwell, J. 2012. *Qualitative Research Design: An Interactive Approach* / J.A. Maxwell.

Mayes, J.M., Mouraviev, V., Tsivian, M., Krupski, T.L., Donatucci, C.F. and Polascik, T.J. 2009. Concordance in the perception of couples recovering from primary surgical treatment of prostate cancer.

## References

*International Journal of Impotence Research* 21(4), pp. 253–260. doi: 10.1038/ijir.2009.23.

McCaughan, E., McKenna, S., McSorley, O. and Parahoo, K. 2015. The experience and perceptions of men with prostate cancer and their partners of the CONNECT psychosocial intervention: a qualitative exploration. *Journal of Advanced Nursing* 71(8), pp. 1871–1882. doi: 10.1111/jan.12648.

McCorkle, R., Ercolano, E., Lazenby, M., Schulman-Green, D., Schilling, L.S., Lorig, K. and Wagner, E.H. 2011. Self-management: Enabling and empowering patients living with cancer as a chronic illness. *CA: A Cancer Journal for Clinicians* 61(1), pp. 50–62. doi: 10.3322/caac.20093.

McLeod, J. 2003. *Doing Counselling Research*. SAGE Publications. Available at: <https://books.google.com.mt/books?id=aViDa0wLGPIC>.

Merriel, S.W.D., Funston, G. and Hamilton, W. 2018. Prostate Cancer in Primary Care. *Advances in therapy* 35(9), pp. 1285–1294. doi: 10.1007/s12325-018-0766-1.

Mertens, D.M. 2005. *Research and Evaluation in Education and Psychology: Integrating Diversity With Quantitative, Qualitative, and Mixed Methods*. SAGE Publications. Available at: <https://books.google.com.mt/books?id=VEkXBAAAQBAJ>.

Merz, E.L., Malcarne, V.L., Ko, C.M., Sadler, M., Kwack, L., Varni, J.W. and Sadler, G.R. 2011. Dyadic concordance among prostate cancer patients and their partners and health-related quality of life: Does it matter? *Psychology & Health* 26(6), pp. 651–666. doi: 10.1080/08870441003721251

Midtgaard, J., Tjørnhøj-Thomsen, T., Rørth, M., Kronborg, M., Bjerre, E.D. and Oliffe, J.L. 2021. Female partner experiences of prostate cancer patients' engagement with a community-based football intervention: a qualitative study. *BMC Public Health* 21(1), p. 1398. doi: 10.1186/s12889-021-11448-7.

Mifsud, S. 2016. *Gender role perceptions of University of Malta students and how these vary according to demographic factors*. University of Malta. Available at: <https://www.um.edu.mt/library/oar/handle/123456789/14660>.

Miles, M.B., Huberman, A.M. and Saldana, J. 2014. *Qualitative Data Analysis*. SAGE Publications. Available at: <https://books.google.com.mt/books?id=3CNrUbTu6CsC>.

## References

Miller, R.S. and Lefcourt, H.M. 1982. The Assessment of Social Intimacy. *Journal of Personality Assessment* 46(5), pp. 514–518. doi: 10.1207/s15327752jpa4605\_12.

Ministry for Health [Malta] 2017. *The National Cancer Plan for the Maltese Islands 2017-2022*. Available at: <http://www.iccp-portal.org/system/files/plans/MinistryForHealth-Cancer%20Plan.pdf>.

Ministry for Health, the Elderly and Community Care [Malta] 2011. The National Cancer Plan 2011-2015. Available at: [http://www.epaac.eu/from\\_heidi\\_wiki/Malta\\_National\\_Cancer\\_Plan\\_English.pdf](http://www.epaac.eu/from_heidi_wiki/Malta_National_Cancer_Plan_English.pdf) [Accessed: 5 July 2022].

Morehouse, R.E. 2012. *Beginning Interpretive Inquiry: A Step-by-Step Approach to Research and Evaluation*. Taylor & Francis. Available at: <https://books.google.com.mt/books?id=yjFZBwAAQBAJ>.

Morgan, D.L. 1998. *The Focus Group Guidebook*. SAGE Publications. Available at: <https://books.google.com.mt/books?id=5q3k3No59OcC>.

Morgan, D.L., Ataie, J., Carder, P. and Hoffman, K. 2013. Introducing Dyadic Interviews as a Method for Collecting Qualitative Data. *Qualitative Health Research* 23(9), pp. 1276–1284. doi: 10.1177/1049732313501889.

Morris, S.M. 2001. Joint and Individual Interviewing in the Context of Cancer. *Qualitative Health Research* 11(4), pp. 553–567. doi: 10.1177/104973201129119208.

Morris, W.J. et al. 2017. Androgen Suppression Combined with Elective Nodal and Dose Escalated Radiation Therapy (the ASCENDE-RT Trial): An Analysis of Survival Endpoints for a Randomized Trial Comparing a Low-Dose-Rate Brachytherapy Boost to a Dose-Escalated External Beam Boost for High- and Intermediate-risk Prostate Cancer. *International journal of radiation oncology, biology, physics* 98(2), pp. 275–285. doi: 10.1016/j.ijrobp.2016.11.026.

Morrison, S., Ellis, T., Fillingham, E., Song, Y.P. and Birtle, A. 2019. Less to Hold – a Comparison of Bowel and Bladder Toxicities in Patients Undergoing Prostate Radiotherapy between those Treated with an Empty Bladder and those Following a Bladder Filling Protocol. *Clinical Oncology* 31(2), p. e23. doi: 10.1016/j.clon.2018.11.013.

Moses, J.W. and Knutsen, T.L. 2007. *Ways of Knowing: Competing Methodologies in Social and Political Research*.

Mottet, N. et al. 2021. EAU-EANM-ESTRO-ESUR-SIOG Guidelines on Prostate Cancer-2020 Update. Part 1: Screening, Diagnosis, and

## References

Local Treatment with Curative Intent. *European urology* 79(2), pp. 243–262. doi: 10.1016/j.eururo.2020.09.042.

Mukku, S.S.R., Harbishettar, V. and Sivakumar, P.T. 2018. Psychological morbidity after job retirement: A review. *Asian Journal of Psychiatry* 37, pp. 58–63. doi: 10.1016/j.ajp.2018.08.003.

Mullaney, L.M. et al. 2014. A randomized trial comparing bladder volume consistency during fractionated prostate radiation therapy. *Practical Radiation Oncology* 4(5), pp. e203–e212. doi: 10.1016/j.prrro.2013.11.006.

Munro, E.R., Holmes, L. and Ward, H. 2005. Researching Vulnerable Groups: Ethical Issues and the Effective Conduct of Research in Local Authorities. *The British Journal of Social Work* 35(7), pp. 1023–1038. doi: 10.1093/bjsw/bch220.

Nakamura, K., Konishi, K., Komatsu, T. and Ishiba, R. 2019. Quality of life after external beam radiotherapy for localized prostate cancer: Comparison with other modalities. *International Journal of Urology* 26(10), pp. 950–954. doi: 10.1111/iju.14026.

Nanton, V., Osborne, D. and Dale, J. 2010. Maintaining control over illness: a model of partner activity in prostate cancer. *European journal of cancer care* 19(3), pp. 329–339. doi: 10.1111/j.165-2354.2008.01047.x.

Nardini, C. 2014. The ethics of clinical trials. *Ecancermedicalscience* 8, pp. 387–387. doi: 10.3332/ecancer.2014.387.

National Statistics Office [Malta] 2018. *Adult Education Survey: 2016*. National Statistics Office. Available at: <https://books.google.com.mt/books?id=oeLkzQEACAAJ>.

National Statistics Office, Malta 2019. Labour Force Survey: 2019. Available at: [https://nso.gov.mt/en/News\\_Releases/View\\_by\\_Unit/Unit\\_C2/Labour\\_Market\\_Statistics/Documents/2019/News2019\\_101.pdf](https://nso.gov.mt/en/News_Releases/View_by_Unit/Unit_C2/Labour_Market_Statistics/Documents/2019/News2019_101.pdf).

National Statistics Office [Malta] 2021. News release - world population day. Available at: [https://nso.gov.mt/en/News\\_Releases/Documents/2021/07/News2021\\_122.pdf](https://nso.gov.mt/en/News_Releases/Documents/2021/07/News2021_122.pdf).

Neergaard, M.A., Olesen, F., Andersen, R.S. and Sondergaard, J. 2009. Qualitative description - the poor cousin of health research? *BMC medical research methodology* 9, p. 52. doi: 10.1186/1471-2288-9-52.

Nelson, K., Bennett, P. and Rance, J. 2019. The experiences of giving and receiving social support for men with localised prostate cancer

## References

and their partners. *Ecancermedicalscience* 13, pp. 989–989. doi: 10.3332/ecancer.2019.989.

Nguyen, C., Lairson, D.R., Swartz, M.D. and Du, X.L. 2018. Risks of Major Long-Term Side Effects Associated with Androgen-Deprivation Therapy in Men with Prostate Cancer. *Pharmacotherapy* 38(10), pp. 999–1009. doi: 10.1002/phar.2168.

Nipp, R.D. et al. 2016. The relationship between coping strategies, quality of life, and mood in patients with incurable cancer. *Cancer* 122(13), pp. 2110–2116. doi: 10.1002/cncr.30025.

Nissen, N. 2017. Men's Everyday Health Care: Practices, Tensions and Paradoxes, and Masculinities in Denmark. *Medical Anthropology* 36(6), pp. 551–565. doi: 10.1080/01459740.2017.1316981.

Norlyk, A. and Harder, I. 2010. What Makes a Phenomenological Study Phenomenological? An Analysis of Peer-Reviewed Empirical Nursing Studies. *Qualitative Health Research* 20(3), pp. 420–431. doi: 10.1177/1049732309357435.

O'Brien, M.E. and Steele, N.M. 2017. Wife Caregiver Experiences in the Patient with Prostate Cancer at Home. *Urologic nursing* 37(1), pp. 37–44.

Oh, S., Meyerowitz, B.E., Perez, M.A. and Thornton, A.A. 2007. Need for cognition and psychosocial adjustment in prostate cancer patients and partners. *Journal of Psychosocial Oncology* 25(1), pp. 1–19.

O'Kane, P., Smith, A. and Lerman, M.P. 2019. Building Transparency and Trustworthiness in Inductive Research Through Computer-Aided Qualitative Data Analysis Software. *Organizational Research Methods* , p. 1094428119865016. doi: 10.1177/1094428119865016.

O'Leary, Z. 2004. *The Essential Guide to Doing Research*. SAGE Publications. Available at: <https://books.google.com.mt/books?id=ItKeqNfgNW0C>.

Oliffe, J.L., Mróz, L.W., Bottorff, J.L., Braybrook, D.E., Ward, A. and Goldenberg, L.S. 2015. Heterosexual couples and prostate cancer support groups: a gender relations analysis. *Supportive Care in Cancer* 23(4), pp. 1127–1133. doi: 10.1007/s00520-014-2562-z.

Opdenakker, R. 2006. Advantages and Disadvantages of Four Interview Techniques in Qualitative Research. *Forum Qualitative Sozialforschung / Forum: Qualitative Social Research; Vol 7, No 4 (2006): Qualitative Research in Ibero America* DO - 10.17169/fqs-7.4.175 . Available at: <http://www.qualitative-research.net/index.php/fqs/article/view/175/391>.

## References

Orom, H., Biddle, C., Underwood, W., Nelson, C.J. and Homish, D.L. 2016. What Is a “Good” Treatment Decision? Decisional Control, Knowledge, Treatment Decision Making, and Quality of Life in Men with Clinically Localized Prostate Cancer. *Medical Decision Making* 36(6), pp. 714–725. doi: 10.1177/0272989X16635633.

O’Shaughnessy, P.K., Ireland, C., Pelentsov, L., Thomas, L.A. and Esterman, A.J. 2013. Impaired sexual function and prostate cancer: a mixed method investigation into the experiences of men and their partners. *Journal of Clinical Nursing* 22(23–24), pp. 3492–3502. doi: 10.1111/jocn.12190.

O’Shaughnessy, P. k, Laws, T. a and Esterman, A. j 2015. Love, faith and hope – a secondary analysis of prostate cancer survivors and their partners. *Contemporary Nurse: A Journal for the Australian Nursing Profession* 50(2/3), pp. 149–168. doi: 10.1080/10376178.2015.1101352.

Osoba, D., Rodrigues, G., Myles, J., Zee, B. and Pater, J. 1998. Interpreting the significance of changes in health-related quality-of-life scores. *Journal of clinical oncology : official journal of the American Society of Clinical Oncology* 16(1), pp. 139–144. doi: 10.1200/JCO.1998.16.1.139.

Padilla, G.V., Presant, C., Grant, M.M., Metter, G., Lipsett, J. and Heide, F. 1983. Quality of Life Index for Patients with Cancer. *Research in nursing & health* 6(3), pp. 117–126. doi: 10.1002/nur.4770060305.

Padgett, D. 2008. *Qualitative Methods in Social Work Research*. SAGE Publications. Available at: [https://books.google.com.mt/books?id=jVr09K\\_Y-JIC](https://books.google.com.mt/books?id=jVr09K_Y-JIC).

Palmer Kelly, E., Paredes, A.Z., Tsilimigras, D.I., Hyer, J.M. and Pawlik, T.M. 2020. The role of religion and spirituality in cancer care: An umbrella review of the literature. *Surgical Oncology* , p. 101389. doi: 10.1016/j.suronc.2020.05.004.

Parahoo, K. 2008. Research on couples. *Journal of Advanced Nursing* 62(3), pp. 275–275. doi: 10.1111/j.1365-2648.2008.04684.x.

Paterson, C., Jones, M., Rattray, J. and Lauder, W. 2013. Exploring the relationship between coping, social support and health-related quality of life for prostate cancer survivors: a review of the literature. *European journal of oncology nursing : the official journal of European Oncology Nursing Society* 17(6), pp. 750–759. doi: 10.1016/j.ejon.2013.04.002.

Paterson, C., Robertson, A. and Nabi, G. 2015. Exploring prostate cancer survivors’ self-management behaviours and examining the

## References

mechanism effect that links coping and social support to health-related quality of life, anxiety and depression: a prospective longitudinal study. *European journal of oncology nursing: the official journal of European Oncology Nursing Society* 19(2), pp. 120–128. doi: 10.1016/j.ejon.2014.10.008.

Patton, M.Q. 1990. Qualitative evaluation and research methods, 2nd ed. *Qualitative evaluation and research methods, 2nd ed.* , pp. 532–532.

Penedo, F.J., Oswald, L.B., Kronenfeld, J.P., Garcia, S.F., Cella, D. and Yanez, B. 2020. The increasing value of eHealth in the delivery of patient-centred cancer care. *The Lancet Oncology* 21(5), pp. e240–e251. doi: 10.1016/S1470-2045(20)30021-8.

Peters, D.H., Garg, A., Bloom, G., Walker, D.G., Brieger, W.R. and Rahman, M.H. 2008. Poverty and access to health care in developing countries. *Annals of the New York Academy of Sciences* 1136, pp. 161–171. doi: 10.1196/annals.1425.011.

Peterson, C.C. 2013. *Looking Forward Through the Lifespan: Developmental Psychology*. Pearson Higher Education AU. Available at: <https://books.google.com.mt/books?id=NiviBAAAQBAJ>.

Pieterse, A.H., Henselmans, I., de Haes, H.C.J.M., Koning, C.C.E., Geijsen, E.D. and Smets, E.M.A. 2011. Shared decision making: Prostate cancer patients' appraisal of treatment alternatives and oncologists' eliciting and responding behavior, an explorative study. *Patient Education and Counseling* 85(3), pp. e251–e259. doi: 10.1016/j.pec.2011.05.012.

Piscopo, S., Vella, S. and Abela, A. 2020. Couple Relationships in Mediterranean Malta. In: Abela, A., Vella, S., and Piscopo, S. eds. *Couple Relationships in a Global Context: Understanding Love and Intimacy Across Cultures*. Cham: Springer International Publishing, pp. 125–142. Available at: [https://doi.org/10.1007/978-3-030-37712-0\\_8](https://doi.org/10.1007/978-3-030-37712-0_8).

Polgar, S. and Thomas, S.A. 2013. *Introduction to Research in the Health Sciences*. Elsevier Health Sciences. Available at: <https://books.google.com.mt/books?id=DZN5AAAAQBAJ>.

Porter, L., Keefe, F., Hurwitz, H. and Faber, M. 2005. Disclosure between patients with gastrointestinal cancer and their spouses. *Psycho-oncology* 14, pp. 1030–42. doi: 10.1002/pon.915.

Powell, G. and Greenhaus, J. 2010. Sex, Gender, and the Work-to-Family Interface: Exploring Negative and Positive Interdependencies. *Academy of Management Journal* 53, pp. 513–534. doi: 10.5465/AMJ.2010.51468647.

## References

Puchalski, C.M. 2012. Spirituality in the cancer trajectory. *Palliative Care of Cancer: an International Perspective Ankara, Turkey, 2–4 April 2012* 23, pp. iii49–iii55. doi: 10.1093/annonc/mds088.

Pudrovska, T. 2010. Why is Cancer More Depressing for Men than Women among Older White Adults? *Social forces; a scientific medium of social study and interpretation* 89(2), pp. 535–558. doi: 10.1353/sof.2010.0102.

Rabin, C. 2002. *Equal Partners - Good Friends: Empowering Couples Through Therapy*. Taylor & Francis. Available at: <https://books.google.com.mt/books?id=hZCKAgAAQBAJ>.

Racher, F.E. 2003. Using conjoint interviews to research the lived experience of elderly rural couples. *Nurse researcher* 10(3), pp. 60–72. doi: 10.7748/nr2003.04.10.3.60.c5898 [doi].

Ramsey, S.D. et al. 2013. Impact of prostate cancer on sexual relationships: a longitudinal perspective on intimate partners' experiences. *The journal of sexual medicine* 10(12), pp. 3135–3143.

Regan, T.W., Lambert, S.D., Kelly, B., Falconier, M., Kissane, D. and Levesque, J.V. 2015. Couples coping with cancer: exploration of theoretical frameworks from dyadic studies. *Psycho-Oncology* 24(12), pp. 1605–1617. doi: 10.1002/pon.3854.

Regan, T.W., Lambert, S.D., Kelly, B., McElduff, P., Girgis, A., Kayser, K. and Turner, J. 2014. Cross-sectional relationships between dyadic coping and anxiety, depression, and relationship satisfaction for patients with prostate cancer and their spouses. *Patient Education and Counseling* 96(1), pp. 120–127. doi: 10.1016/j.pec.2014.04.010.

Rehman, J. ur et al. 2018. Intensity modulated radiation therapy: A review of current practice and future outlooks. *Journal of Radiation Research and Applied Sciences* 11(4), pp. 361–367. doi: 10.1016/j.jrras.2018.07.006.

Renzi, C. et al. 2017. A Qualitative Investigation on Patient Empowerment in Prostate Cancer. *Frontiers in Psychology* 8, p. 1215. doi: 10.3389/fpsyg.2017.01215.

Resnick, M.J. et al. 2013. Long-Term Functional Outcomes after Treatment for Localized Prostate Cancer. *The New England journal of medicine* 368(5), pp. 436–445. doi: 10.1056/NEJMoa1209978.

Revenson, T.A. 1994. Social support and marital coping with chronic illness. *Annals of Behavioral Medicine* 16(2), pp. 122–130.

Robson, C. 2011. *Real World Research*. Wiley. Available at: <https://books.google.com.mt/books?id=fbhIRwAACAAJ>.



## References

Roch, M. et al. 2019. Impact of rectum and bladder anatomy in intrafractional prostate motion during hypofractionated radiation therapy. *Clinical & translational oncology: official publication of the Federation of Spanish Oncology Societies and of the National Cancer Institute of Mexico* 21(5), pp. 607–614. doi: 10.1007/s12094-018-1960-y.

Rodday, A.M. et al. 2015. Impact of patient navigation in eliminating economic disparities in cancer care. *Cancer* 121(22), pp. 4025–4034. doi: 10.1002/cncr.29612.

Rosen, R.C., Riley, A., Wagner, G., Osterloh, I.H., Kirkpatrick, J. and Mishra, A. 1997. The international index of erectile function (IIEF): a multidimensional scale for assessment of erectile dysfunction. *Urology* 49(6), pp. 822–830. doi: 10.1016/s0090-4295(97)00238-0.

Ross, K.M., Ranby, K.W., Wooldridge, J.S., Robertson, C. and Lipkus, I.M. 2016. Effects of physical and mental health on relationship satisfaction: a dyadic, longitudinal examination of couples facing prostate cancer. *Psycho-Oncology* 25(8), pp. 898–904. doi: 10.1002/pon.3931.

Saldaña, J. 2009. The coding manual for qualitative researchers. *The coding manual for qualitative researchers.* , pp. xi, 223–xi, 223.

Sandelowski, M. 1993. Rigor or rigor mortis: the problem of rigor in qualitative research revisited. *ANS:Advances in nursing science* 16(2), pp. 1–8.

Sandelowski, M. 2000. Whatever happened to qualitative description? *Research in Nursing & Health* 23(4), pp. 334–340. doi: 10.1002/1098-240X(200008)23:4<334::AID-NUR9>3.0.CO;2-G.

Sandelowski, M. 2010. What's in a name? Qualitative description revisited. *Research in Nursing & Health* 33(1), pp. 77–84. doi: 10.1002/nur.20362.

Sanders, S., Pedro, L.W., Bantum, E.O. and Galbraith, M.E. 2006. Couples surviving prostate cancer: Long-term intimacy needs and concerns following treatment. *Clinical journal of oncology nursing* 10(4), pp. 503–508. doi: 10.1188/06.CJON.503-508.

Satariano, B. and Curtis, S.E. 2018. The experience of social determinants of health within a Southern European Maltese culture. *Health & Place* 51, pp. 45–51. doi: 10.1016/j.healthplace.2018.02.011.

Schindler, I., Berg, C.A., Butler, J.M., Fortenberry, K.T. and Wiebe, D.J. 2010. Late-Midlife and Older Couples' Shared Possible Selves and Psychological Well-being During Times of Illness: The Role of

## References

Collaborative Problem Solving. *Journals of Gerontology: Series B: Psychological Sciences and Social Sciences* 65B(4), pp. 416–424.

Schwandt, T. 2007. The SAGE Dictionary of Qualitative Inquiry. Available at: <https://methods.sagepub.com/reference/the-sage-dictionary-of-qualitative-inquiry>.

Sefik, E. et al. 2020. Anxiety and depression associated with a positive prostate biopsy result: A comparative, prospective cohort study. *International braz j urol: official journal of the Brazilian Society of Urology* 46(6), pp. 993–1005. doi: 10.1590/S1677-5538.IBJU.2019.0719.

Shacham, S. 1983. A shortened version of the Profile of Mood States. *Journal of personality assessment* 47(3), pp. 305–306. doi: 10.1207/s15327752jpa4703\_14.

Shrout, M.R. et al. 2020. Relationship satisfaction predicts lower stress and inflammation in breast cancer survivors: A longitudinal study of within-person and between-person effects. *Psychoneuroendocrinology* 118, p. 104708. doi: 10.1016/j.psyneuen.2020.104708.

Sieber, J.E. 1992. Planning ethically responsible research: A guide for students and internal review boards. *Planning ethically responsible research: A guide for students and internal review boards.*, pp. xii, 163–xii, 163.

Silverman, D. 2013. *Doing Qualitative Research: A Practical Handbook*. SAGE Publications. Available at: <https://books.google.com.mt/books?id=THdpBAAQBAJ>.

Sinfield, P., Baker, R., Agarwal, S. and Tarrant, C. 2008. Patient-centred care: What are the experiences of prostate cancer patients and their partners? *Patient Education and Counseling* 73(1), pp. 91–96. doi: 10.1016/j.pec.2008.05.001.

Skyring, T.A., Mansfield, K.J. and Mullan, J.R. 2021. Factors Affecting Satisfaction with the Decision-Making Process and Decision Regret for Men with a New Diagnosis of Prostate Cancer. *American journal of men's health* 15(4), pp. 15579883211026812–15579883211026812. doi: 10.1177/15579883211026812.

Smith, G.A. et al. 2022. Bladder filling in patients undergoing prostate radiotherapy on a MR-linac: The dosimetric impact. *Technical Innovations & Patient Support in Radiation Oncology* 21, pp. 41–45. doi: 10.1016/j.tipsro.2022.02.002.

## References

- Smith, T.W. et al. 2009. Conflict and collaboration in middle-aged and older couples: II. Cardiovascular reactivity during marital interaction. *Psychology and aging* 24(2), pp. 274–286. doi: 10.1037/a0016067.
- Smythe, W.E. and Murray, M.J. 2000. Owning the Story: Ethical Considerations in Narrative Research. *Ethics & Behavior* 10(4), pp. 311–336. doi: 10.1207/S15327019EB1004\_1.
- Sohier, P. 1995. The dyadic interview as a tool for nursing research. *Applied nursing research: ANR* 8, pp. 96–101. doi: 10.1016/S0897-1897(95)80562-1.
- Song, L., Northouse, L.L., Braun, T.M., Zhang, L., Cimprich, B., Ronis, D.L. and Mood, D.W. 2011. Assessing longitudinal quality of life in prostate cancer patients and their spouses: a multilevel modeling approach. *Quality of Life Research* 20(3), pp. 371–381. doi: 10.1007/s11136-010-9753-y.
- Song, L., Northouse, L.L., Zhang, L., Braun, T.M., Cimprich, B., Ronis, D.L. and Mood, D.W. 2012. Study of dyadic communication in couples managing prostate cancer: A longitudinal perspective. *Psycho-Oncology* 21(1), pp. 72–81. doi: 10.1002/pon.1861.
- Song, L., Rini, C., Ellis, K. and Northouse, L. 2016. Appraisals, perceived dyadic communication, and quality of life over time among couples coping with prostate cancer. *Supportive Care in Cancer* 24(9), pp. 3757–3765. doi: 10.1007/s00520-016-3188-0.
- Sousa, A.D., Sonavane, S. and Mehta, J. 2012. Psychological aspects of prostate cancer: a clinical review. *Prostate Cancer and Prostatic Diseases* 15(2), pp. 120–127. doi: 10.1038/pcan.2011.66.
- Spanier, G.B. 1976. Measuring Dyadic Adjustment: New Scales for Assessing the Quality of Marriage and Similar Dyads. *Journal of Marriage and Family* 38(1), pp. 15–28. doi: 10.2307/350547.
- Spradley, J.P. 2016. *The Ethnographic Interview*. Waveland Press. Available at: <https://books.google.com/mt/books?id=KZ3ICwAAQBAJ>.
- Stacey, D. et al. 2014. Decision aids for people facing health treatment or screening decisions. *The Cochrane database of systematic reviews* (1), p. CD001431. doi: 10.1002/14651858.CD001431.pub4.
- Stake, R.E. 1995. *The Art of Case Study Research*. SAGE Publications. Available at: <https://books.google.com/mt/books?id=ApGdBx76b9kC>.
- van Stam, M.-A., Pieterse, A.H., van der Poel, H.G., Bosch, J.L.H.R., Tillier, C., Horenblas, S. and Aaronson, N.K. 2018. Shared Decision Making in Prostate Cancer Care-Encouraging Every Patient to be Actively Involved in Decision Making or Ensuring the Patient Preferred

## References

Level of Involvement? *The Journal of urology* 200(3), pp. 582–589. doi: 10.1016/j.juro.2018.02.3091.

Stam, M.R., van Lin, E.N.J.T., van der Vight, L.P., Kaanders, J.H.A.M. and Visser, A.G. 2006. Bladder filling variation during radiation treatment of prostate cancer: can the use of a bladder ultrasound scanner and biofeedback optimize bladder filling? *International journal of radiation oncology, biology, physics* 65(2), pp. 371–377. doi: 10.1016/j.ijrobp.2005.12.039.

Stefan and Laspina 2015. *THE SIR ANTHONY MAMO ONCOLOGY CENTRE*. Available at: <https://www.um.edu.mt/healthsciences/mjhs>.

Stiggelbout, A.M. et al. 2012. Shared decision making: really putting patients at the centre of healthcare. *BMJ* 344, p. e256. doi: 10.1136/bmj.e256.

Stiggelbout, A.M., Pieterse, A.H. and De Haes, J.C.J.M. 2015. Shared decision making: Concepts, evidence, and practice. *Patient education and counseling* 98(10), pp. 1172–1179. doi: 10.1016/j.pec.2015.06.022.

Sullivan-Bolyai, S., Bova, C. and Harper, D. 2005. Developing and refining interventions in persons with health disparities: The use of Qualitative Description. *Nursing Outlook* 53(3), pp. 127–133. doi: 10.1016/j.outlook.2005.03.005.

Sung, H., Ferlay, J., Siegel, R.L., Laversanne, M., Soerjomataram, I., Jemal, A. and Bray, F. 2021. Global Cancer Statistics 2020: GLOBOCAN Estimates of Incidence and Mortality Worldwide for 36 Cancers in 185 Countries. *CA: A Cancer Journal for Clinicians* 71(3), pp. 209–249. doi: 10.3322/caac.21660.

Sutton, E. et al. 2021. Men's experiences of radiotherapy treatment for localized prostate cancer and its long-term treatment side effects: a longitudinal qualitative study. *Cancer Causes & Control* 32(3), pp. 261–269. doi: 10.1007/s10552-020-01380-3.

Taylor, B. and de Vocht, H. 2011. Interviewing separately or as couples? Considerations of authenticity of method. *Qualitative health research* 21(11), pp. 1576–1587. doi: 10.1177/1049732311415288.

Teh, Y.Y. and Lek, E. 2018. Culture and reflexivity: systemic journeys with a British Chinese family. *Journal of Family Therapy* 40(4), pp. 520–536. doi: 10.1111/1467-6427.12205.

Temple, B. and Edwards, R. 2008. Interpreters/Translators and Cross-Language Research: Reflexivity and Border Crossings. *International Journal of Qualitative Methods* 1, pp. 1–12. doi: 10.1177/160940690200100201.

## References

Tortell, A. 2022. Malta's Government Does Not Care About Sexual Health, Here's Why. Available at: <https://lovinmalta.com/lifestyle/health/sexual-health/maltas-government-does-not-care-about-sexual-health-heres-why/> [Accessed: 24 November 2022].

Traa, M.J., De Vries, J., Bodenmann, G. and Den Oudsten, B.L. 2015. Dyadic coping and relationship functioning in couples coping with cancer: A systematic review. *British Journal of Health Psychology* 20(1), pp. 85–114. doi: 10.1111/bjhp.12094.

Tsai, J.H.-C., Choe, J.H., Lim, J.M.C., Acorda, E., Chan, N.L., Taylor, V. and Tu, S.-P. 2004. Developing Culturally Competent Health Knowledge: Issues of Data Analysis of Cross-Cultural, Cross-Language Qualitative Research. *International Journal of Qualitative Methods* 3(4), pp. 16–27. doi: 10.1177/160940690400300402.

Tsivian, M., Mayes, J.M., Krupski, T.L., Mouraviev, V., Donatucci, C.F. and Polascik, T.J. 2009. Altered male physiologic function after surgery for prostate cancer: couple perspective. *International braz j urol : official journal of the Brazilian Society of Urology* 35(6), pp. 673–682. doi: 10.1590/s1677-55382009000600006.

Valentine, G. 1999. Doing Household Research: Interviewing Couples Together and Apart. *Area* 31(1), pp. 67–74.

Van Dam, D., Wassersug, R.J. and Hamilton, L.D. 2016. Androgen deprivation therapy's impact on the mood of prostate cancer patients as perceived by patients and the partners of patients. *Psycho-oncology* 25(7), pp. 848–856. doi: 10.1002/pon.3932.

Van den Hoonaard, W. 2003. Is Anonymity an Artifact in Ethnographic Research? *Journal of Academic Ethics* 1, pp. 141–151. doi: 10.1023/B:JAET.0000006919.58804.4c.

Varner, S., Lloyd, G., Ranby, K.W., Callan, S., Robertson, C. and Lipkus, I.M. 2019. Illness uncertainty, partner support, and quality of life: A dyadic longitudinal investigation of couples facing prostate cancer. *Psycho-oncology* 28(11), pp. 2188–2194. doi: 10.1002/pon.5205.

Vassallo, M. 2016. The Social and Employment Situation in Malta., p. 40.

Velikova, G., Fallowfield, L., Younger, J., Board, R.E. and Selby, P. 2018. *Problem Solving in Patient-Centred and Integrated Cancer Care*. EBN Health. Available at: <https://books.google.com.mt/books?id=yMqFDwAAQBAJ>.

## References

- Viani, G.A., Viana, B.S., Martin, J.E.C., Rossi, B.T., Zuliani, G. and Stefano, E.J. 2016. Intensity-modulated radiotherapy reduces toxicity with similar biochemical control compared with 3-dimensional conformal radiotherapy for prostate cancer: A randomized clinical trial. *Cancer* 122(13), pp. 2004–2011. doi: 10.1002/cncr.29983.
- Violette, P.D. et al. 2015. Decision aids for localized prostate cancer treatment choice: Systematic review and meta-analysis. *CA: a cancer journal for clinicians* 65(3), pp. 239–251. doi: 10.3322/caac.21272.
- Vodermaier, A. and Linden, W. 2019. Social support buffers against anxiety and depressive symptoms in patients with cancer only if support is wanted: a large sample replication. *Supportive Care in Cancer* 27(7), pp. 2345–2347. doi: 10.1007/s00520-019-04737-w.
- Walford, G. 2005. Research ethical guidelines and anonymity. *International Journal of Research & Method in Education* 28(1), pp. 83–93. doi: 10.1080/01406720500036786.
- Walker, A.C., Tan, L. and George, S. 1995. Impact of culture on pain management: an Australian nursing perspective. *Holistic nursing practice* 9(2), pp. 48–57. doi: 10.1097/00004650-199501000-00008.
- Walker, L.M. and Robinson, J.W. 2010. The unique needs of couples experiencing androgen deprivation therapy for prostate cancer. *Journal of Sex & Marital Therapy* 36(2), pp. 154–165. doi: 10.1080/00926230903554552.
- Walker, L.M. and Robinson, J.W. 2011. A description of heterosexual couples' sexual adjustment to androgen deprivation therapy for prostate cancer. *Psycho-Oncology* 20(8), pp. 880–888. doi: 10.1002/pon.1794.
- Wall, D. and Kristjanson, L. 2005. Men, culture and hegemonic masculinity: understanding the experience of prostate cancer. *Nursing Inquiry* 12(2), pp. 87–97.
- Walz, J. et al. 2016. A Critical Analysis of the Current Knowledge of Surgical Anatomy of the Prostate Related to Optimisation of Cancer Control and Preservation of Continence and Erection in Candidates for Radical Prostatectomy: An Update. *European urology* 70(2), pp. 301–311. doi: 10.1016/j.eururo.2016.01.026.
- Ware, J.E. and Sherbourne, C.D. 1992. The MOS 36-Item Short-Form Health Survey (SF-36): I. Conceptual Framework and Item Selection. *Medical care* 30(6), pp. 473–483.
- Watts, S., Leydon, G., Birch, B., Prescott, P., Lai, L., Eardley, S. and Lewith, G. 2014. Depression and anxiety in prostate cancer: a

## References

systematic review and meta-analysis of prevalence rates. *BMJ open* 4(3), p. e003901. doi: 10.1136/bmjopen-2013-003901.

Weber, A.M. et al. 2019. Gender norms and health: insights from global survey data. *The Lancet* 393(10189), pp. 2455–2468.

van Weert, J.C.M., van Munster, B.C., Sanders, R., Spijker, R., Hooft, L. and Jansen, J. 2016. Decision aids to help older people make health decisions: a systematic review and meta-analysis. *BMC Medical Informatics and Decision Making* 16(1), p. 45. doi: 10.1186/s12911-016-0281-8.

Wei, J.T., Dunn, R.L., Litwin, M.S., Sandler, H.M. and Sanda, M.G. 2000. Development and validation of the expanded prostate cancer index composite (EPIC) for comprehensive assessment of health-related quality of life in men with prostate cancer. *Urology* 56(6), pp. 899–905. doi: 10.1016/S0090-4295(00)00858-X.

van der Weijden, T. et al. 2022. Shared decision-making in the Netherlands: Progress is made, but not for all. Time to become inclusive to patients. *Zeitschrift für Evidenz, Fortbildung und Qualität im Gesundheitswesen* 171, pp. 98–104. doi: 10.1016/j.zefq.2022.04.029.

Weiss, D.S. 2007. The Impact of Event Scale: Revised. *Cross-cultural assessment of psychological trauma and PTSD.* , pp. 219–238. doi: 10.1007/978-0-387-70990-1\_10.

Whiting, L.S. 2008. Semi-structured interviews: guidance for novice researchers. *Nursing Standard* 22(23), pp. 35–40. doi: 10.7748/ns2008.02.22.23.35.c6420.

Wibowo, E., Wassersug, R.J., Robinson, J.W., Matthew, A., McLeod, D. and Walker, L.M. 2019. How Are Patients With Prostate Cancer Managing Androgen Deprivation Therapy Side Effects? *Clinical Genitourinary Cancer* 17(3), pp. e408–e419. doi: 10.1016/j.clgc.2018.12.006.

Wiegel, T. et al. 2015. Prostate-specific antigen persistence after radical prostatectomy as a predictive factor of clinical relapse-free survival and overall survival: 10-year data of the ARO 96-02 trial. *International journal of radiation oncology, biology, physics* 91(2), pp. 288–294. doi: 10.1016/j.ijrobp.2014.09.039.

Wight, D. 1994. Boys' thoughts and talk about sex in a working class locality of Glasgow. *The Sociological Review* 42(4), pp. 703–737. doi: 10.1111/j.1467-954X.1994.tb00107.x.

Wiles, R., Crow, G., Heath, S. and Charles, V. 2008. The Management of Confidentiality and Anonymity in Social Research. *International*

## References

*Journal of Social Research Methodology* 11(5), pp. 417–428. doi: 10.1080/13645570701622231.

Williams, G.R. et al. 2019. Unmet social support needs among older adults with cancer. *Cancer* 125(3), pp. 473–481. doi: 10.1002/cncr.31809.

Willis, J.W., Jost, M. and Nilakanta, R. 2007. *Foundations of Qualitative Research: Interpretive and Critical Approaches*. SAGE Publications. Available at: <https://books.google.com.mt/books?id=dWJMXUkQukIC>.

Winters-Stone, K.M., Lyons, K.S., Bennett, J.A. and Beer, T.M. 2014. Patterns and predictors of symptom incongruence in older couples coping with prostate cancer. *Supportive Care in Cancer: Official Journal of the Multinational Association of Supportive Care in Cancer* 22(5), pp. 1341–1348. doi: 10.1007/s00520-013-2092-0.

Wittmann, D. et al. 2015. What Couples Say about Their Recovery of Sexual Intimacy after Prostatectomy: Toward the Development of a Conceptual Model of Couples' Sexual Recovery after Surgery for Prostate Cancer. *The Journal of Sexual Medicine* 12(2), pp. 494–504. doi: //dx.doi.org/10.1111/jsm.12732.

Wittmann, D., Carolan, M., Given, B., Skolarus, T.A., An, L., Palapattu, G. and Montie, J.E. 2014. Exploring the role of the partner in couples' sexual recovery after surgery for prostate cancer. *Supportive care in cancer: official journal of the Multinational Association of Supportive Care in Cancer* 22(9), pp. 2509–2515. doi: 10.1007/s00520-014-2244-x.

Wood, A., Barden, S., Terk, M. and Cesaretti, J. 2019. Prostate cancer: the influence of stigma on quality of life and relationship satisfaction for survivors and their partners. *Journal of psychosocial oncology* 37(3), pp. 350–366. doi: 10.1080/07347332.2018.1489442.

Wootten, A.C., Abbott, J.M., Osborne, D., Austin, D.W., Klein, B., Costello, A.J. and Murphy, D.G. 2014. The impact of prostate cancer on partners: a qualitative exploration. *Psycho-Oncology* 23(11), pp. 1252–1258. doi: 10.1002/pon.3552.

World Health Organisation 2022a. Malta 'nurse navigators' embodied patient-centred care. Available at: <https://www.who.int/europe/news/item/15-09-2022-malta--nurse-navigators--embody-patient-centred-care>.

World Health Organisation 2022b. Noncommunicable diseases. Available at: <https://www.who.int/news-room/fact-sheets/detail/noncommunicable-diseases> [Accessed: 10 November 2022].



## References

World Medical Association 2013. World Medical Association Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects. *JAMA* 310(20), p. 2191. doi: 10.1001/jama.2013.281053.

Wright, P. et al. 2019. Key factors associated with social distress after prostate cancer: Results from the United Kingdom Life after Prostate Cancer diagnosis study. *Cancer Epidemiology* 60, pp. 201–207. doi: 10.1016/j.canep.2019.04.006.

Wu, L.M., Mohamed, N.E., Winkel, G. and Diefenbach, M.A. 2013. Patient and spouse illness beliefs and quality of life in prostate cancer patients. *Psychology & Health* 28(4), pp. 355–368. doi: 10.1080/08870446.2012.722219.

Yiannopoulou, K.G., Anastasiou, A.I., Kontoangelos, K., Papageorgiou, C. and Anastasiou, I.P. 2020. Cognitive and Psychological Impacts of Different Treatment Options for Prostate Cancer: A Critical Analysis. *Current Urology* 14(4), pp. 169–177. doi: 10.1159/000499242.

Yin 2003. *Case Study Research: Design and Methods*. Sage.

Yu Ko, W.F., Oliffe, J.L. and Bottorff, J.L. 2020. Prostate Cancer Treatment and Work: A Scoping Review. *American journal of men's health* 14(6), pp. 1557988320979257–1557988320979257. doi: 10.1177/1557988320979257.

Zaorsky, N.G. et al. 2017. The evolution of brachytherapy for prostate cancer. *Nature reviews. Urology* 14(7), pp. 415–439. doi: 10.1038/nrurol.2017.76.

Zee, K.S. and Bolger, N. 2019. Visible and Invisible Social Support: How, Why, and When. *Current Directions in Psychological Science* 28(3), pp. 314–320. doi: 10.1177/0963721419835214.

Zigmond, A.S. and Snaith, R.P. 1983. The hospital anxiety and depression scale. *Acta psychiatrica Scandinavica* 67(6), pp. 361–370. doi: 10.1111/j.1600-0447.1983.tb09716.x.

## **APPENDIX ONE – LITERATURE REVIEW AND SYNTHESIS OF THE LITERATURE**

As a vast body of literature was identified and this was further synthesised for each category and reviewed using the CASP tool. Following discussion with the supervisory team, criteria were developed that were used to identify articles for the main body of evidence, with the remaining articles to be used as supporting evidence.

All articles were downloaded, and a summary of each articles provided further information that could be used for the synthesis of the literature. As specific questions were formulated for the literature synthesis, articles were further divided into one of the following categories:

- What is the impact of a prostate cancer diagnosis and treatment on the quality-of-life scores of couples over time?
- Are there age-specific differences when dealing with a prostate cancer diagnosis and treatment from a couple's perspective?
- What is the impact of different treatment option on the adjustment of couples?
- What is the impact of a prostate cancer diagnosis and treatment on couples' life and relationship?

For each of these categories specific criteria were developed which will be further presented below for each individual literature research question.

**1 - What is the impact of a prostate cancer diagnosis and treatment on the quality-of-life scores of couples over time?**

In order to identify a suitable time period for this current study I was interested what is currently known about the physical and psychological changes over time. In particular, at what time period couples may experience the greatest changes and in order to identify any gaps in the literature that could be targeted by this study. To identify changes over time, several criteria were drafted that could help to identify the main body of evidence and these included:

- Longitudinal studies that minimally included 2 assessment periods including baseline assessments prior treatment to identify changes over time
- Quantitative studies to compare findings and scores
- Quality of Life assessment that included both members of the couple to identify physical and psychological functioning over time

Appendix one – Literature review and synthesis of the literature

Author and year	Location	Study design	Sample size and technique	Data collection tools	Data analysis	Main findings	recommendation
Song et al. (2012)	USA	Longitudinal (baseline at 4, 8 and 12 months)	134 couples, surgery, RT (ADT+chemo)	Communication (MIS), social support (PRQ), Uncertainty (MUIS), side effects (EPIC)	Patterns of change in communication and to determine factors that affect this communication	Communication decreased over time with similar trends between male and female.	Communication is affected by certain baseline and time-varying psychosocial and cancer-related factors.
Ross et al. (2016)	USA	Longitudinal (baseline, 1, 6 and 12 months)	159 couples, Surgery only	Relationship satisfaction (MQI), physical health (MOS) and mental health (MOS)	How mental and physical health relates to relationship satisfaction.	Couples had initial decline at 1 month, with some improvements noted at 6 and 12	Patient and partner recorded a decline in their relationship satisfaction.
Wu et al. (2013)	USA	Longitudinal (baseline and at 6 months)	53 couples, RT, surgery and BT	Treatment control and illness beliefs (IPQ-R), Quality of life (FACT-G)	How impact beliefs affect the QoL scores of couples	Spouse illness beliefs improved patient QoL but this did not occur for patients' beliefs	Spouse illness beliefs may impact patient QoL scores highlighting the dyadic impact of pca

Appendix one – Literature review and synthesis of the literature

Ezer et al. (2011)	Canada	Longitudinal (baseline, 3 and 12 months)	81 couples, RT + surgery	Psychosocial adjustment to illness (PAIS), Profile of mood state (POMS), sense of coherence (SOC), Prostate cancer Index score (PSSE) and quality of social support scale (QSSS)	To determine the psychosocial adjustment congruent between couples in the first year after pca treatment	Psychological incongruent was noted at all time points with little variation in congruence over time.	Findings suggest that couples incongruence was observed in several domains such as psychological and sexual domain which may be targeted for clinical intervention
Galbraith et al. (2008)	USA	Longitudinal (baseline, 6, 12 and 18 months)	216 couples, surgery, RT, Proton and mixed	Quality of Life (QLI), general measure of health status (SF-36) and dyadic adjustment scale (DAS)	To describe health-related outcomes of couples dealing with prostate	Patient scores were associated with partner scores more than 50% over the time, with an initial reduction until	This study identified a reciprocal pattern of influence between the dyads throughout the study suggesting the partners should be

Appendix one – Literature review and synthesis of the literature

					cancer over time	12months with some recovery at 18 months	actively included in the provision of information.
Song et al. (2011)	USA	Longitudinal (baseline, 4, 8 and 12 months)	134 couples, newly diagnosed, biochemical recurrence and advanced disease	Quality of Life (FACT-G), Communication (MIS), Prostate cancer symptoms (EPIC) and general symptoms (RFD)	To examine relationship of QoL in patients and partners and how time and psychosocial and symptoms vary.	Over time, the QoL improved as their social support and cancer-related communication increased and uncertainty and side effect decreased	QoL is affected by contextual factors (e.g. demographics and time varying psychosocial factors). Comprehensive strategies is needed to improve QoL
Manne et al. (2021)	USA	Longitudinal (baseline, 5, 12 and 26 weeks)	81 couples, RT, surgery or ADT within the last 18 months	Depressive symptoms (PHQ), psychological adjustment (MHI), Cancer distress (IES), mutual avoidance (CPQ), Prostate cancer symptoms (PCI)	To examine how communication impact the psychosocial adjustment of couples over time	Higher disclosure predicted better psychological outcomes and less mutual avoidance and holding back predicted poorer psychological adjustment.	Couples cancer-specific relationship communication predicted their psychological adjustment. Poorer communication during initial had poorer psychological outcomes

Appendix one – Literature review and synthesis of the literature

							with slightly improved over time
Chien et al. (2019)	Taiwan	Longitudinal (baseline, 6, 8, 18 and 24 weeks)	48 couples, surgery or RT	Dyadic adjustment (DAS), medical outcome health survey (SF-12), anxiety scale (MAMX-P) and positive and negative affect (PANAS)	To explore HRQOL and its individual or mutual influence in people with cancer and their spouse	Better HRQOL was reported in individuals with higher positive affect and lower anxiety levels. Better mental was detected in spouses who had higher relationship satisfaction	Improving the HRQOL of men and their spouses by implementing activities that promote health and energy and reduces stress
Harju et al. (2018)	Finland	Longitudinal (baseline and at 6 months)	350 couples, surgery, RT and ADT	Marital questionnaire, health survey (RAND-36), Dyadic adjustment scale (DAS),	To examine changes in relationship 6 months after diagnosis of pca	Patients and spouse reported lower marital satisfaction at 6 months. Spouses reported that their marital relationship had suffered whereas patient reported that it remained unchanged	These findings may be used when counselling for patients and their spouses

Appendix one – Literature review and synthesis of the literature

<p>Varner et al. (2019)</p>	<p>USA</p>	<p>Longitudinal (baseline, 1,6 and 12 months)</p>	<p>165 couples, surgery only</p>	<p>Illness uncertainty scale (IUS), perceived support (Social provision Scale), relationship satisfaction (MQI) and physical and mental quality of life (SF-36)</p>	<p>To investigate the association between psychosocial constructs and the impact on their QoL scores</p>	<p>Partner feeling more supported at diagnosis felt more supported at 6 months. Partner reports of support at 6 months predicted patients' 12 months mental QoL and relationship satisfaction.</p>	<p>Findings indicate the psychological interdependence between the Pca patients and their spouses. Interventions should include both member and may target illness uncertainty</p>
<p>Kersaw et al. (2008)</p>	<p>USA</p>	<p>Longitudinal (baseline, 4 and 8 months)</p>	<p>121 couples, newly diagnosed, biochemical recurrence and advanced disease</p>	<p>Quality of Life (MOS SF-12), Coping (BriefCOPE), social support (PRQ), general symptoms (OSQ) and</p>	<p>To examine stress coping model to determine if baseline appraisal predicted coping and quality of life</p>	<p>Patients personal, social and illness-related variables had the most impact on their negative appraisal and qol. The older the spouse the more negative appraisal of illness and uncertainty reported by patient</p>	<p>Several specific predictors were identified that could be targeted to improve the qol for men and partner such as self-efficacy and that spouses may need more assistance in using effective coping strategies when in their caregiving role.</p>



Appendix one – Literature review and synthesis of the literature

Eismann et al. (2013)	Germany	Longitudinal (baseline, 3, 6, 12 and 24 months)	293 couples, surgery and RT	Quality of Life (QLQ-30), health status (SF-12), relationship quality (self-designed), social support (PORPUS) and anxiety and depression (EQ-5D)	To describe the QoL after a diagnosis of pca over time and to identify the effects of predictors of partners QoL	Men's QoL had a small but significant impact on partners QoL and partner QoL score was mostly affected by partners' physical and psychological health and relationship quality.	Findings of this study suggest that Average QoL increased after 3 months and several factors were identified that impact partners QoL that may be used for interventions.
Keller (2017)	Germany	Longitudinal (Baseline, 1, 3, 5, and 7 months)	209 couples, surgery only	Dyadic planning, burden of urinary side effects, ICIF-SF), self-efficacy, patient/partner effect, relationship satisfaction (RAS)	Evaluation of framework to determine predictors in the context of pelvic floor exercises	Findings revealed that context, target person and relationship factors were associated with dyadic planning whereas positive or negative effects were not.	Partner factors did not prevail as unique predictors in dyadic planning of pelvic floor exercises following Pca surgery.
Couper et al. (2006)	Australia	Longitudinal (at diagnosis)	103 couples, localised and	Anxiety and depression (CIDI), brief symptom	To assess the psychosocial impact of the	Partners had higher rates of anxiety and depression at baseline	interventions aimed at reducing the morbidity of PCA must involve both

Appendix one – Literature review and synthesis of the literature

		and 6 months after)	metastatic disease	inventory (BSI), Dyadic adjustment scale (DAS)	diagnosis of either localised or metastatic prostate cancer (PCA) on patients and their female partners	and this was increased for the partners at time 2, however an increase was noted in the patients scores at this time period.	patient and partner, rather than the patient alone
Song et al. (2016)	USA	Longitudinal (baseline assessment, 4 and 8 months)	124 couples	Appraisal of illness scale, perceived dyadic communication, quality of life (FACT-G)	To assess the interdependent relationships between their appraisals of illness and QOL, and if their perceived dyadic communication mediated these relationships	Spouses with more negative appraisal at baseline had worse dyadic communication at 4 months and worse QoL at 8 months. Patient and spouse that who perceived more dyadic communication at 4 months had better QoL score at 8 months	Patients' and spouses' appraisals of the illness and their dyadic communication were associated with their QoL scores. Interventions that reduce negative appraisal and promote dyadic communication may improve the QoL scores of men and spouse

Appendix one – Literature review and synthesis of the literature

Appendix one – Literature review and synthesis of the literature

	Song et al. (2012)	Ross et al. (2016)	Wu et al. (2013)	Ezer et al. (2011)	Galbraith et al. (2008)	Song et al. (2011)	Manne et al. (2021)	Chien et al. (2019)	Harju et al. (2018)
CASP criteria (cohort study)									
Global quality rating	7/12	9/12	7/12	7/12	9/12	9/12	8/12	10/12	9/12
Clear focussed issue?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Cohort recruited in an acceptable way?	?	Yes	Yes	?	yes	?	No	Yes	Yes
Exposure accurately measured to minimize bias?	Yes	Yes	Yes	Yes	Yes	Yes	yes	Yes	Yes
Outcome accurately measured to minimize bias?	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes
Confounding factors been taken into account?	?	?	Yes	No	No	Yes	Yes	Yes	?
Was the follow up complete/long enough?	Yes	Yes	No	?	Yes	Yes	Yes	Yes	Yes
Are the results valid?	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes
Are the results precise?	No	?	Yes	?	?	?	Yes	?	Yes

Appendix one – Literature review and synthesis of the literature

Do you believe the results?	Yes	Yes	?	Yes	Yes	Yes	Yes	Yes	?
Can the results be applied locally?	?	?	?	?	?	?	?	?	?
Do the results fit in other available evidence	?	Yes	Yes	Yes	Yes	yes	no	Yes	Yes
What are the implications?	Yes	No	yes	yes	yes	yes	?	Yes	Yes

Appendix one – Literature review and synthesis of the literature

	Varner et al. (2019)	Kershaw et al. (2008)	Eismann et al. (2013)	Keller (2017)	Couper et al. (2006)	Song et al. (2016)
CASP criteria (cohort study)						
Global quality rating	7/12	6/12	10/12	6/12	7/12	10/12
Clear focussed issue?	Yes	yes	Yes	Yes	yes	Yes
Cohort recruited in an acceptable way?	Yes	?	Yes	?	yes	Yes
Exposure accurately measured to minimize bias?	Yes	Yes	Yes	?	?	yes
Outcome accurately measured to minimize bias?	?	yes	Yes	Yes	Yes	yes
Confounding factors been taken into account?	?	?	Yes	Yes	?	?
Was the follow-up complete/long enough?	Yes	yes	Yes	?	?	Yes
Are the results valid?	No	?	Yes	Yes	Yes	yes

Appendix one – Literature review and synthesis of the literature

Are the results precise?	?	?	Yes	?	Yes	yes
Do you believe the results?	Yes	?	yes	Yes	Yes	yes
Can the results be applied locally?	?	?	?	?	?	?
Do the results fit in other available evidence	Yes	yes	yes	Yes	Yes	yes
What are the implications?	Yes	yes	no	?	?	yes

## **1 - Summary of appraisal and CASP review**

Following the initial search, a total of 15 articles (see above) were identified that included quantitative studies that used a longitudinal approach and therefore could provide further detail and information regarding the impact on time on the adjustment of couples.

Three of these articles did not include an assessment of the QoL but focused on other aspects such as the communication process (Song et al. 2012; Manne et al. 2021) or how the urine side effects change over time (Keller et al. 2017). These studies were therefore not used as the main body of evidence but used to provide further insights on the impact of prostate cancer treatment over time. Two studies (Couper et al. 2006; Ezer et al. 2011) specifically focused on the psychosocial impact of prostate cancer on couples and therefore did not investigate other aspects of QoL that may be important in the adjustment to prostate cancer.

The remaining 10 were appraised using the CASP tool and evaluation of these articles revealed that 3 articles included participants from 3 phases of illness (newly diagnosed, recurrence or advanced prostate cancer) (Kershaw et al. 2008; Song et al. 2011; Song et al. 2016). Therefore, although these studies reported baseline findings and findings over time, some of these couples (recurrence and advanced) could have been living with prostate cancer for a longer period of time which may impact their adjustment to prostate cancer.

From the remaining 7 articles, it was found that further 3 articles the primary focus was not on the QoL score, but these studies investigated how other variables may influence the QoL score, such as the marital relationship (Harju et al. 2018), how impact beliefs affected the QoL (Wu et al. 2013; Varner et al. 2019), or couples relationship satisfaction (Ross et al. 2016; Chien et al. 2019). These studies were included as they could provide further insight into factors that may influence the QoL score of the man and spouse, they were not used as the main body of evidence.



## Appendix one – Literature review and synthesis of the literature

Two articles only investigated the quality of life of couples over time (Eisemann et al. 2013 and Galbraith et al. 2008), with the remaining articles investigating how different aspects may impact the quality of life scores such as anxiety or marital relationship.

**2- Are there age-specific differences when dealing with a prostate cancer diagnosis and treatment from a couple's perspective?**

In order to identify age specific needs and/or differences between age groups in dealing with a prostate cancer diagnosis and treatment I identified studies that focused or included specific age groups in their study design. In particular, I wanted to identify if there are any age-specific needs or differences and to identify any gaps in the literature that could be targeted by this study. Several criteria were drafted that could help to identify the main body of evidence and these included:

- Specific inclusion criteria or age groups needed to be defined in the study design and/or data analysis.
- Both quantitative, qualitative and or mixed studies design were included.

Appendix one – Literature review and synthesis of the literature

Author and year	Location	Study design	Age-group	Sample size and technique	Data collection tools	Data analysis	Main findings	recommendation
Harden et al. (2006)	USA	Qualitative interviews	Three groups (50-64, 65-74, 75-84)	15 couples in each cohort with men newly diagnosed, biochemical recurrence or advanced disease)	Semi-structured interviews – couples joint interviews	Data analysis process provided and included initial codes and reading of transcript for recurrent ideas but no further details provided	Couples in the late middle age group reported greater disappointment and anger at their inability to reach life goals and establish financial security. Couples in the young-old group made more spontaneous comments about being satisfied with their life than the couples in the other 2 groups. Couples in the old-	Prostate cancer may have some universal effects on couples, it also may have differential effects by age cohort. Hence, targeted interventions by age cohort may be warranted.

Appendix one – Literature review and synthesis of the literature

							old group reported slower recovery from the illness than the younger couples	
Harden et al. (2008)	USA	Cross sectional survey	Three groups 50-64 late middle age, 65-74 young-old and 75-84 old-old	69 couples, newly diagnosed, biochemical recurrence or advanced disease	Quality of life (MOS SF-12), Prostate side effects (EPIC), Self-efficacy (CASE) and concurrent concerns (OSQ)	to examine how qol, self-efficacy and appraisal vary among men with prostate cancer according to age cohort	patients 65–74 had better QOL and higher self-efficacy than patients ages 50–64 and less negative appraisal of illness than the other two age groups	Interventions should be tailored to dyads' developmental life stage. Younger and older prostate cancer survivors and their partners may benefit from tailored interventions designed to improve their quality of life
Winters-Stone (2014)	USA	Cross-sectional survey	Older couples >60 years	59 couples, RT, ADT, chemotherapy	Prostate cancer symptoms (PCS), Depressive symptoms (CES-	To examine symptom congruence in older couples	Couples varied significantly in their severity rating. Younger age and high caregiver	Younger age and caregiver strain were associated with symptom incongruence and

Appendix one – Literature review and synthesis of the literature

					D) and caregiver strain.	coping with Pca.	strain accounted for 29% of incongruence	could be targeted for future interventions.
Schindler (2010)	USA	Cross-sectional survey	Late mid-life couples <70 years and older couples >70 years	61 couples, RT, surgery	Shared possible selves, perceptions of collaborations (PCQ), psychological well being and marital quality (DAS)	To investigate the associations between shared possible selves and well-being in couples and differences between age groups (<70 vs <70 for men)	Shared selves were associated with better well-being only with frequent collaboration was obtained with older couples	Infrequent collaboration was associated with poor marital quality and interventions aimed at improving the marital relationship should be especially beneficial in distressed couples
Collaço (2021)	UK	Qualitative	<65 years	28 couples	Semi-structured telephone interviews were conducted with twenty-eight couples,	Interviews were transcribed verbatim, and thematic analysis using the Framework	couples' experienced changes in their intimate relationships, parental/familial	Several areas for support were identified such as couple focused support program and age-specific support

Appendix one – Literature review and synthesis of the literature

					separately (56 participants).	Method. interpreting of dyadic data was informed by Eisikovits and Koren.	roles, work and finances, and social connections and activities. Several strategies and behaviours to aid their adjustment to PCa, such as communicating with each other, distancing, distraction, and adopting a positive mindset towards	such as a buddying system which can connect younger couples and providing them with tailored made support
Collaço (2019)	UK	Qualitative	<65 years	23 men and partner	Semi-structured telephone interviews were conducted with twenty-eight couples,	Interviews were transcribed verbatim, and thematic analysis using the Framework Method.	Younger couples affected by prostate cancer felt challenged by issues relating to their parental role and the dynamics	Support programmes offering guidance to children/young adults affected by prostate cancer in their family, and addressing the concerns of parents

Appendix one – Literature review and synthesis of the literature

					separately (56 participants).	Interpreting of dyadic data was informed by Eisikovits and Koren.	within the family. Difficult conversations about prostate cancer diagnosis; perceptions of the impact of diagnosis on children; parental responses to the impact of PCa on the family.	may help families to better adapt.
--	--	--	--	--	-------------------------------	---	--	------------------------------------

Appendix one – Literature review and synthesis of the literature

	Collaço (2019)	Collaço (2021)	Harden et al. (2006)		Schindler (2010)	Winters-Stone (2014)	Harden et al. (2008)
CASP criteria (qualitative research)				CASP criteria (cohort study)			
Global quality rating	9/10	9/10	7/10	Global quality rating	9/12	11/12	8/12
Clear Aims?	Yes	Yes	Yes	Clear focussed issue?	Yes	Yes	Yes
Qualitative methodology appropriate	Yes	Yes	Yes	Cohort recruited in an acceptable way?	Yes	Yes	?
Research design appropriate for address aims?	Yes	Yes	Yes	Exposure accurately measured to minimize bias?	Yes	Yes	Yes
Appropriate recruitment strategy?	Yes	Yes	?	Outcome accurately measured to minimize bias?	Yes	Yes	Yes
Data collection appropriate?	Yes	Yes	yes	Confounding factors been	?	yes	?



Appendix one – Literature review and synthesis of the literature

				taken into account?			
Relationship between research and participants considered?	?	?	?	Was the follow-up complete/long enough?	Yes	Yes	?
Ethical issues considered?	Yes	yes	yes	Are the results valid?	Yes	Yes	Yes
Data analysis sufficiently rigour?	Yes	yes	?	Are the results precise?	Yes	Yes	Yes
Clear statement of findings?	Yes	yes	Yes	Do you believe the results?	yes	Yes	Yes
Valuable research?	Yes	yes	Yes	Can the results be applied locally?	?	?	?
				Do the results fit in other available evidence	Yes	Yes	Yes
				What are the implications?	?	Yes	Yes

## **2 –Overview of studies**

Following the initial search, a total of six articles (see above) were identified that specifically focused on a particular age group or investigated age-specific differences between age groups when dealing with a prostate cancer diagnosis and treatment. This included both quantitative (n=3) as well as qualitative studies (n=3). However, when appraising these articles, Winterstone (2014) included men who were 60 years or older and therefore only excluded younger men <60 years and spouses. Schindler et al. (2010) included all age groups in the study and divided them following data collection in two groups <70 and >70 years of age. However, it was not clear why these particular age-groups or categories were selected.

The qualitative studies included Harden et al. (2006) who investigated three age groups according to the development life stage. This included late-middle age (50-64 age), young-old group (65-74 age) and old-old (75-84). Similarly, Collaco et al. (2018, 2020) focused on younger men and spouses and used the age-groups as identified by Harden et al. (2008). For the main body of evidence, the qualitative studies were chosen as these could provide additional in-depth information on the impact of age on couples dealing with the consequences of prostate cancer, with the remaining quantitative studies included to provide further context.

**3- What is the impact of different treatment option on the adjustment of couples?**

As each treatment modality for prostate cancer has their own unique side effect profile, the impact and adjustment to these may vary. Therefore, studies that were designed for specific treatment modalities or that specifically compared different treatment modalities were included in this section. The following criteria were drafted to identify these studies:

- Recruitment of participants was limited to a specific treatment options.
- Studies those in the design of their study comparing different treatment options were also included.

Appendix one – Literature review and synthesis of the literature

Qualitative studies								
Author and year	Location	Study design	Treatment option	Sample size and technique	Data collection tools	Data analysis	Main findings	recommendation
Wittman (2015)	USA	Qualitative, pre-operative and 3 months post-operative	Post-surgery (robotic-assisted radical prostatectomy)	20 couples, pre and post-surgery.	Semi-structured interview with the couples followed by brief individual interviews	Analytic Induction approach to analyze interview data and build sexual recovery theory	Faith in themselves and their surgeons led 90% of couples to overestimate erectile recovery. Post-operatively, most men had ED and lost confidence with Couples' sexual activity decreased	Couples' sexual recovery requires addressing sexual function, feelings about losses and relationship simultaneously.
Walker and Robinson (2011)	Canada	Qualitative	ADT (hormone treatment)	18 couples	Open-ended, unstructured interviews of approximately 1 h in length	A grounded theory methodology was utilized to extract themes that	Three distinct patterns were identified, one group assumed sex to be impossible	Some couples are able to enjoy satisfying sex, despite castrate levels of testosterone, raised questions about how

Appendix one – Literature review and synthesis of the literature

					were conducted with each couple	emerged in the dialogue	after commencing ADT Another group was found to be struggling to either maintain satisfying sex or adapt to the loss of their sexual The third group had struggled, but found that they were satisfied with their sexual outcome (nine couples	patients are prepared to undergo ADT and how they are managed.
Quantitative studies								
Author and year	Location	Study design	Treatment option	Sample size and technique	Data collection tools	Data analysis	Main findings	recommendation
Hamilton et al. (2016)	Canada	Quantitative cohort study	Comparison of ADT and non-ADT	206 men (50ADT and 156 non-ADT) and 66 partners (33	To assess mood (POMS), dyadic adjustment scale (DAS),	To compare how treatment type, patient mood, and sexual function related to dyadic	Men on ADT reported better dyadic adjustment. ADT experienced greater bother at	Both patients and partners are impacted by the prostate cancer treatment effects

Appendix one – Literature review and synthesis of the literature

				ADT and 33 non-ADT)	sex life was measured using subscale of EPIC	adjustment from patient and partner perspectives	loss of sexual function than patients not on ADT. patients' mood predicted their dyadic adjustment, such that worse mood was related to worse dyadic adjustment	onpatients' psychological and sexual function
Chambers (2013)	Australia	Quantitative cohort study	Surgery only	186 couples	Prostate cancer index (UCLA), Masucline self-esteem scale, revised dyadic adjustment scale, anxiety and depression (HADS), Quality of life	Mean difference tests and chi-squared analyses were conducted on continuous and categorical variables to compare demographic variables for	Patients and partners reported low distress with, female partners were more anxious with 36 % reporting mild to severe anxiety. For female partners, the man's psychological distress and his sexual bother were	The correlates of distress after the diagnosis of prostate cancer differ between patients and female partners. For men, masculine self-esteem may be most crucial, whereas for women, her partner's level of distress may matter most

Appendix one – Literature review and synthesis of the literature

					(SF-36), distress (IES- R)	patients and their partners.	most strongly related to her mental health status.	
Mayes et al. (2009)	USA	Quantitative cohort study	Surgery only	28 couples	Retrospective Sexual Survey (RSS), International Index of Erectile Function (IIEF), and Female Sexual Function Index (FSFI)	concordance in couples recovering from primary surgical treatment of prostate on emotional status, relationship, self image, partnership quality and support	Partnership had the highest concordance with treatment satisfaction questions focused on self-image, relationship, support and emotional status, were less concordant.	Although couples report relationships as strong and team-like, misconception between partners is widespread.
Tsivian et al. (2009)	USA	Quantitative cohort study	Surgery only	28 couples	Retrospective Sexual Survey (RSS), International Index of	To investigate the perspectives and concordance regarding male physiological	40% of men and women were happy with their levels of sexual interest with 82% concordance.	Patients and their female partners may interpret differently the same physiological outcomes of PCa surgery. This

Appendix one – Literature review and synthesis of the literature

					Erectile Function (IIEF), and Female Sexual Function Index (FSFI)	function from the standpoint of the couple	Urine loss during orgasm was reported by 43% of men; the majority of participants were bothered by it. Ejaculation changes were observed by 96% of men (concordance 96%) with most reporting anejaculation	information could be useful to better counsel the PCa couple and help patients and partners adjust after surgery.
Van Dam et al. (2016)	Canada	Quantitative cohort study	ADT compared to non-ADT	295 patients (213 non-ADT, 82 ADT) and 84 spouses (42 non-ADT, 42 ADT) completed the online survey	Self-designed health questionnaire Health measures included questions about PCa	To assess the relationship between of androgen deprivation therapy (ADT) and the mood of prostate cancer	Patients currently treated with ADT (n= 82) reported worsened mood as measured by the Profile of Mood States compared to those not on ADT	ADT's impact on PCa patients' mood and verify that partners concurrently see the effects. The psychological changes related to ADT can impact relationships and



Appendix one – Literature review and synthesis of the literature

					<p>treatments and adverse effect. To assess mood (POMS), dyadic adjustment scale (DAS), sex life was measured using subscale of EPIC</p>	<p>(PCa) patients and partners of PCa patients</p>	<p>(n= 213). The negative impact of ADT on mood, however, was reduced in older patients</p>	<p>affect the quality of life of both PCa patients and partners</p>
--	--	--	--	--	--	--	---	---

Appendix one – Literature review and synthesis of the literature

	Wittman (2015)	Walker and Robinson (2011)		Hamilton et al. (2016)	Van Dam et al. (2016)	Tsivian et al. (2009)	Mayes et al. (2009)	Chambers (2013)
CASP criteria (qualitative research)			CASP criteria (cohort study)					
Global quality rating	8/10	7/10	Global quality rating	9/12	10/12	7/12	7/12	10/12
Clear Aims?	Yes	Yes	Clear focussed issue?	Yes	Yes	yes	Yes	Yes
Qualitative methodology appropriate	Yes	Yes	Cohort recruited in an acceptable way?	?	?	?	?	Yes
Research design appropriate for address aims?	Yes	Yes	Exposure accurately measured to minimize bias?	Yes	Yes	Yes	Yes	Yes
Appropriate recruitment strategy?	Yes	?	Outcome accurately measured to minimize bias?	Yes	Yes	Yes	Yes	Yes
Data collection appropriate?	Yes	Yes	Confounding factors been	?	Yes	no	No	?

Appendix one – Literature review and synthesis of the literature

			taken into account?					
Relationship between research and participants considered?	No	No	Was the follow-up complete/long enough?	Yes	Yes	yes	Yes	Yes
Ethical issues considered?	Yes	Yes	Are the results valid?	Yes	Yes	?	?	Yes
Data analysis sufficiently rigour?	?	?	Are the results precise?	Yes	Yes	yes	Yes	Yes
Clear statement of findings?	Yes	Yes	Do you believe the results?	Yes	Yes	yes	Yes	Yes
Valuable research?	Yes	Yes	Can the results be applied locally?	?	?	?	?	?
			Do the results fit in other available evidence	Yes	Yes	yes	Yes	Yes
			What are the implications?	Yes	Yes	No	No	Yes

### **3 –Overview of studies and selection of main body of evidence**

Following the initial search, 7 studies focused on specific treatment modalities, with a mix of qualitative (n=2) and quantitative studies (n=5). The majority of these studies focused on couples who were dealing with surgery (n=4), followed by ADT (n=1). In addition, 2 studies specifically compared two groups ADT vs. non-ADT groups.

The two qualitative studies included one study specifically on couples recovery following prostatectomy (Wittmann et al. 2015) and ADT (Walker and Robinson 2011) and both these studies investigated couples sexual recovery following treatment. In addition, two quantitative studies (Mayes et al. 2009; Tsivian et al. 2009) also focused on the sexual recovery following prostatectomy. Although sexual side effects and recovery from sexual side effects may be an important for couples, these studies may not provide detail and information about other aspects in the recovery process and therefore were not included as the main body of evidence but to support the narrative.

The remaining three quantitative studies were selected as the main body of evidence, with two studies specifically comparing the use of ADT with non-ADT (Hamilton et al. 2016; Van Dam et al. 2016) and can provide additional detail regarding the different outcomes of these treatment options. In addition, Chambers et al. (2013) investigated more general distress levels of men and spouse following prostatectomy and was also included in the main body of evidence.

#### **4- What is the impact of a diagnosis and treatment on couples life and relationship?**

The remaining qualitative (n=11), quantitative (n=11) and one mixed-method study were included in this final section that looked at the impact of a diagnosis and treatment on couples' life and relationship. The main body of evidence focused on the qualitative studies to provide an in-depth understanding of the impact on the life and relationship of couples. To identify the main body of evidence, the qualitative studies were critically appraised using the CASP tool and the remaining studies were used to provide further insight into the phenomena.

Appendix one – Literature review and synthesis of the literature

Qualitative studies								
Author and year	Location	Area of investigation	Study design	Sample size and technique	Data collection tools	Data analysis	Main findings	recommendation
Fergus (2011)	Canada	How the experience affected couples identity	Qualitative couples were purposively recruited to be well adjusted (high scores on DAS scale)	5 couples (mixed) – couples were interviewed on two occasions to elicit their account (on average 10 weeks apart)	5 couples interviews	The grounded theory analysis was used. The text was divided into individual units of analysis or “meaning units”. Each MU was labelled using an “embodied categorization” procedure	The core category to emerge from this analysis of the couple’s experience with prostate cancer was the Rupture and Repair of the Couple’s Communal Body defined by three main domains: (1) Riding the Vortex; (2) Holding the Communal Body Intact; and (3) Invincibility and its Underbelly.	It is concluded that the inter subjective embodiment displayed by couples in this study was instrumental to the “repair” of the communal body ruptured by prostate cancer.

Appendix one – Literature review and synthesis of the literature

Docherty (2007)	UK	Inadequate knowledge	Qualitative – focus group interview	12 couples – from support group members	Two focus group interviews first (5 men and 1 woman) and second (4 men and 2 woman)	A qualitative thematic approach was conducted including initial theme, issue and category identification, cross categorization, and axial and selective coding, in addition to the identification of positive and negative incidents as a means to enhancing validity	inadequacies in patient and spouse knowledge and awareness of prostate cancer contributed to delayed contact, shock at diagnosis, preferences regarding decision making, health judgments, including the use of the Prostate Specific Antigen test and physical well-being as accurate health indicators, and patient coping, incorporating the use of comparison with other patients	hospital staff, in particular the consultant and cancer nurse specialist, must be aware of the potential for inadequacy in patient and spouse knowledge and counter this through the provision of accurate and relevant information and support throughout the medical process
-----------------	----	----------------------	-------------------------------------	---	---	---	---	--

Appendix one – Literature review and synthesis of the literature

<p>Beck et al. (2013)</p>	<p>Canada</p>	<p>Intimacy/sexual</p>	<p>Qualitative – in-depth interview</p>	<p>17 couples (mixed treatment)                       Purposely recruited First, couples who reported being able to restore satisfying sexual intimacy were sought. Then, couples who reported not being able to restore satisfying sexual intimacy were recruited</p>	<p>Initial couple interviews followed by individual in-depth interviews 1 week to 3 months later</p>	<p>The interviews were analyzed using a grounded theory methodology as outlined by Strauss and Corbin</p>	<p>The couples who valued sex primarily for relational intimacy were more likely to successfully adjust to changes in sexual function than those who primarily valued sex for physical pleasure. The attributes of acceptance, flexibility, and persistence helped sustain couples through the process of adjustment. Based on these findings, a new theory, the Physical Pleasure–Relational Intimacy Model of Sexual Motivation (PRISM) is presented</p>	<p>The PRISM model can also be used to inform clinical interventions.</p>
---------------------------	---------------	------------------------	---	--	--	---	--	---



Appendix one – Literature review and synthesis of the literature

Nanton (2010)	UK	Partner involvement in pca – secondary analysis	Qualitative – couple interviews	15 men (9 couples)	Individual interview with men (with 9 spouses attending the session)	The analysis of transcripts was guided by techniques derived from branches of pragmatics and qualitative social research, both underpinned by constructionist approaches to social reality	Although the men’s personal ‘story’ was the focus of each interview, wives ensured that an accurate account of events and their timing was given. Findings suggest a model of partner activity in prostate cancer conceptualized as ‘maintaining control over illness’	In the clinical setting, attention to the interaction between partners may facilitate appropriate communication strategies by health professionals, leading to more effective information exchange
O’Shaughnessy (2015)	Australia	To explore love, hope and faith in couples	Qualitative – focus group and interviews	30 participants (21 men and 9 woman)	Four focus groups (2 men only and 2 with couples) and 3 couple interviews	A literature search enabled the researchers to produce an analytical framework.	Men not only wanted to be able to express love, they valued feeling loved especially when distressed by a disease process like cancer. men in this study viewed sex not	Findings from this study can be employed to refine psychosocial assessments of men with prostate cancer, and provide a more

Appendix one – Literature review and synthesis of the literature

							only as a function, or a way of receiving pleasure, but also making love was a key language for these men to express their love for their partner	comprehensive understanding of prostate cancer survivors supportive care needs.
Oliffe (2015)	Canada	Supportive care / support groups	Qualitative interviews	30 participant (15men and partner) from support group	Individual semi-structured interviews accounts with 30 participants	Analysis was guided by interpretive descriptive traditions of qualitative research. Couples' accounts were interpreted, as carefully navigating traditional heterosexual gender relations while enabling	Findings showed that traditional heterosexual gender relations guided most couples' PCa-related support both in and out of PCSGs. Three themes were inductively derived: "Not pushing too hard"—balancing women's support with men's autonomy, "Confreres"—men supporting men at	Couples both aligned to and resisted traditional gender roles to accommodate, explain, and rationalize how, as a couple, they approached PCa supportive care needs.

Appendix one – Literature review and synthesis of the literature

						men and their partners to gain the health supports they needed.	PCSGs, and “Women are better at reassuring”—support from and for women	
Sanders (2006)	USA	Intimacy/sexual/couple	Qualitative – focus groups	10 couples	Focus group 3 session of 30 minutes each as a couples and individual men and spouse	Analysis of the narrative from the focus group suggested that men and woman think and respond very differently to the experience of surviving prostate cancer	Findings suggested that men and women think and respond differently to intimacy and relationship challenges that occur as a result of prostate cancer, diagnosis, and treatment.	healthcare providers in any clinical setting who may interact with prostate cancer survivors must consider the relationship and intimacy needs that are unique to men, women, and couples.
Kelly et al. (2015)	UK	Intimacy/sexual	Qualitative interviews	8 couples and 2 individual men (2 years after	Interviews, 6 couples agreed to couples	Analysis proceeded with a full reading and discussion	Four categories were identified that illustrated the impact of prostate cancer on	A relational models of care should be considered,

Appendix one – Literature review and synthesis of the literature

				completion of treatment)	interviews, two couples provided individual account and 2 men agreed to participate alone	between two of the researchers to support the organisation of the interview transcripts Data were coded and comparisons made across the transcripts about couples' experiences since treatment, expectations and views of current service provision regarding recovery following prostate cancer treatment	intimacy and sexual recovery. These related to social influences and language used to describe the loss or recovery of sexual activities; difficulties in discussing sexual activity with clinicians; the clash of individual impact of prostate cancer recovery versus the impact on the couple, and the re-integration of sexual activities into the relationship	whereby side-effects are recognised as impacting on both members of the partnership (for example ED, or lack or ejaculate). Supportive care in this context, therefore, may best be based on a relational approach using language and interventions that are appropriate to the patient and their situation
--	--	--	--	--------------------------	---	--	---	---

Appendix one – Literature review and synthesis of the literature

Forbat (2011)	UK	Discussing sexual consequences in the clinic	Qualitative – ethnographic observation	60 consultations (men and partner)	Ethnographic observation involving men and spouses	Interpretative and descriptive analysis drew on the principles of ethnography. Detailed observational notes recorded the nature and range of topics discussed and whether it was the patient, partner or healthcare professional who had raised the subject of sexual recovery	Sexual functioning was discussed infrequently in both clinic settings and the involvement of the spouses tended to be minimal. Discussions of wider psychosexual concerns were marginalised in consultations, and there were limited opportunities for couples to discuss the specific impact of prostate cancer and its treatments on sexual functioning	Given the potential burden of symptoms and side-effects, there is a need to include discussions of sexual recovery and rehabilitation consultations, and to provide opportunities to discuss the sexual consequences of treatment with men and their partners
Nelson (2019)	UK	Supportive care	Qualitative interview (initial diagnoses,	18 couples	Interviews, couples given choice of individual	The analysis was conducted in three parts, utilising thematic analysis	Support networks for couples became smaller as time progressed. Stigma	The findings expand our understanding of the support

Appendix one – Literature review and synthesis of the literature

		needs/couple	3 months and 1 year)		or joint (11 individual and 7 couples interviews)	approaches. Experiences of men and partners were compared and contrasted at each time point. This provided an understanding of the individual experiences, which were then brought together under an umbrella theme to represent the coupled experience.	was seen to have a role in men's disclosure decisions. Partners generally provided higher levels of support than they received back. For partners, there appeared to be a fine line between disclosing their true feelings and protecting their partner, and they appeared to struggle to access meaningful emotional support and accept instrumental support from trusted others	between couples in the months following diagnosis. Social support groups were highlighted as an important source of support. Further research is now needed to help identify which couples may benefit from professional encouragement to attend these groups
Bamidele (2019)	UK	Psychosocial	Qualitative interviews with couples	25 men, 11 partners and 11 HCP	Semi-structured individual interview with	Data were analysed using constant comparison,	The main theme "man in the driving seat," describes the experiences of BA/BC	Inclusive and culturally sensitive individual and couple-focused

Appendix one – Literature review and synthesis of the literature

		impact/couple	and focus groups with HCP		men and spouse and two focus group interview with Healthcare professionals	which involved iteratively comparing codes, emergent categories, and memos with further data until theoretical saturation was achieved	men with CaP and their partners within their context. Culturally informed gender roles and identities influenced how men and partners responded and coped with the side effects of CaP treatment.	psychosocial support, which is devoid of stereotyping and recognises the experiences of both BA/BC men and their partners is recommended
--	--	---------------	---------------------------	--	--	--	---	--

Appendix one – Literature review and synthesis of the literature

Quantitative studies							
Author and year	Location	Study design	Sample size and technique	Data collection tools	Data analysis / aim of study	Main findings	recommendation
Fagundes (2012)	USA	Cohort survey (Baseline and over 14 days)	59 couples	Intrusive thoughts scale, avoidance scale of the impact event scale and negative affect scale	To study how intrusive thoughts of prostate cancer and avoidance related to their own and each other's average negative affect over a subsequent 14-day period.	Both patients and their wives who had high levels of intrusive thoughts experienced less negative affect when the other member of the couple also experienced high levels of intrusive thoughts. Those who had higher levels of avoidance had spouses who had higher levels of	Congruence in responses to cancer may be adaptive for intrusion but not avoidance because the use of intrusive thoughts by both husbands and wives can allow couples to process the diagnosis of cancer, facilitating psychological adjustment, whereas avoidance does not



Appendix one – Literature review and synthesis of the literature

						negative affect regardless of their own levels of avoidance	
Manne (2015)	USA	Cross-sectional	139 couples	Medical information erectile functioning (ITEF-EF), urinary function (PCI) and holding back sharing concerns, relationship intimacy (PAIR), mental health Inventory and Dyadic adjustment Scale.	To evaluated intimacy as a mechanism for the effects of holding back sharing concerns about cancer on couples' psychological distress, well-being, and marital satisfaction using the actor-partner interdependence model (APIM)	Holding back has strong associations with both partners' well-being and distress. Holding back sharing concerns was particularly detrimental for couples' intimacy and relationship satisfaction.	Clinicians may benefit from reducing holding back and work to improve intimacy in couples where patient, partner, or both, evidence elevated cancer-specific distress.

Appendix one – Literature review and synthesis of the literature

Garos (2007)	USA	Cross-sectional	77 patients and 59 partners	Depression (BDI-II), life satisfaction (LSI-Z), sexual satisfaction (ISS), relationship assessment (RAS). Dyadic sexual communication (DSCS) and client satisfaction (CSQ-8)	To evaluate to what extent partners' psychosocial and relational adjustment relates to prostate cancer patient adjustment	Patients and their partners differed in their sexual self-esteem, sexual depression, sexual preoccupation, and life satisfaction. Both had greater levels of depression, poorer quality of sexual communication, and more sexual dissatisfaction than the general population	Results suggest the importance of including partners' adjustment in assessing patient adjustment post-treatment. Physicians could work with these couples and mental health professionals who can help couples address the challenges they encounter and extend the continuity of care when the need for medical intervention has passed.
Merz et al. (2011)	USA	Cross-sectional	164 men and partner	Prostate cancer index (PCI), health survey (SF-36), dyadic	To evaluate the level of disagreement between men and spouse in the appraisal of pca	Patient and partner PC appraisal ratings were positively correlated. There was a general	Results suggest that dyadic disagreement is associated with worse HRQOL in couples facing PC and this may therefore be a clinically

Appendix one – Literature review and synthesis of the literature

				adjustment scale (DAS)	related symptoms and the outcome on their dyadic adjustment	pattern of patients and partners in concordant dyads, versus those in dyads in which spouses maximized or minimized PC characteristics, reporting significantly better individual HRQOL outcomes	important point of intervention.
Regan et al. (2014)	Australia	Cross-sectional	44 men and partners	Dyadic coping inventory (DCI), relationship satisfaction (R-DAS), anxiety and depression (HADS),	This study investigated if dyadic coping and supportive dyadic coping would be associated with	Relationship satisfaction was significantly associated with patients' and wives' use of positive and negative dyadic coping, and	Couples respond to a prostate cancer diagnosis as an interactional system. Future research should focus on tailoring couple-

Appendix one – Literature review and synthesis of the literature

					<p>lower levels of anxiety and depression and greater relationship</p> <p>Satisfaction for patients and their spouses.</p>	<p>their partners' use of these strategies.</p> <p>partner's use of supportive dyadic coping</p> <p>was associated with anxiety and depression</p>	<p>based interventions such that patients and spouses are equipped to provide the specific support their partners need</p>
Berg (2008)	USA	Cross-sectional (over 14 days)	57 couples	Dyadic adjustment scale (DAS), perceptions of collaboration questionnaire, cognitive abilities and depression (HADS) and a diary to report on aspects of dyadic coping	The study examined the daily processes of collaborative coping (individuals' perceptions that the spouse collaborated), perceived coping effectiveness (ratings of how well they dealt	Collaborative coping was associated with more positive same-day mood for both husbands and wives and less negative mood for wives only. These associations were partially mediated by heightened perceptions of	The results suggest that older couples may benefit from collaborative coping in dealing with problems surrounding illness

Appendix one – Literature review and synthesis of the literature

					with the event), and mood (i.e., Positive and Negative Affect Scale) across 14 days in 57 older couples coping with stressors involving the husband's prostate cancer and daily life in general	<p>coping effectiveness.</p> <p>Exploratory analyses revealed that collaborative coping was more frequent among wives who performed more poorly on cognitive tests and couples who reported greater marital satisfaction and more frequently using collaboration to make decisions</p>	
Manne (2010)	USA	Cross-sectional	75 men and partner	Erectile, bowel and urinary function (IIEF and PCI), self-disclosure,	The present study evaluated intimacy as a mechanism for the effects of	The association between mutual constructive communication, mutual avoidance,	Relationship intimacy and how patients and partners communicate to achieve this intimacy is important for the

Appendix one – Literature review and synthesis of the literature

				mutual constructive communication (CPQ), mutual avoidance (CPQ), holding back and relationship adjustment (DAS)	relationship enhancing (self-disclosure, mutual constructive communication) and relationship-compromising communication (holding back, mutual avoidance, and demand-withdraw communication) on couples' psychological distress.	and patient demand-partner withdraw and distress could be accounted for by their influence on relationship intimacy. Self disclosure, holding back, and partner demand-patient withdraw did not mediate the associations between communication and distress.	psychological adjustment of early stage prostate cancer survivors and their partners.
Badr and Taylor (2009)	USA	Cross-sectional	116 couples	Patient sexual function (IIEF), partner sexual functioning	To characterize the sexual function of both prostate cancer	Patients and partners reported high rates of sexual dysfunction. Within	Although some couples may be reluctant to engage in constructive cancer-related

Appendix one – Literature review and synthesis of the literature

				(FSFI), marital adjustment (DAS), psychological distress and communication patterns	patients and their partners, and to examine whether associations between sexual dysfunction and psychosocial adjustment vary depending on spousal communication patterns.	couples, patients' and their partners' sexual function was moderately to highly correlated ( $r = 0.30-0.74$ ). When patients had poor erectile function, their partners were more likely to report that the couple avoided open spousal discussions; this in turn was associated with partners' marital distress	discussions about sexual problems, such discussions may help alleviate the negative impact that sexual problems have on prostate cancer patients' and their partners' marital adjustment.
Berg (2011)	USA	Cross-sectional	59 couples	Diary - a daily paper diary assessed aspects of dyadic coping	to examine the daily covariation of negative and positive affect	On days when wives experienced greater negative affect, husbands	negative affect covariation may be most likely when spouses experience

Appendix one – Literature review and synthesis of the literature

				<p>At the end of each day the husbands and wives first described the most bothersome event of the day dealing with prostate cancer. If the participants did not have a bothersome event dealing with prostate cancer, they reported the most bothersome event of the day.</p>	<p>among husbands and wives and whether this covariation was enhanced when couples mentioned the same stressful event and reported frequently collaborating</p>	<p>did so as well. However, negative affect covariation was only found when spouses mentioned the same daily stressful event. The mean levels of collaborative coping across the 14 days moderated this negative covariation effect for wives, such that negative affect covariation was enhanced when wives reported collaborating more frequently. Positive</p>	<p>similar stressors and wives perceive frequently collaborating. Partners within close relationships experience similar negative affect as their spouse, pointing to the shared nature of illness in late life.</p>
--	--	--	--	---	---	---	--



Appendix one – Literature review and synthesis of the literature

						affect covariation was not found.	
Grondhuis Palacios (2018)	Netherlands	Cross – sectional	253 men and 174 partners	Self-designed questionnaires by the authors, based on the aim and literature. Consisted of 47 items assessing topics such as socio-demographic factors, sexual function (SF) and satisfaction regarding current sexual health care and desired sexual health management.	To determine which health care provider and what timing is considered most suitable to discuss sexual and relational changes after prostate cancer treatment according to the point of view of men and their partners.	High percentage of men suffered from moderate to severe erectile dysfunction. Half of them were treated for erectile dysfunction. Half of the partners found it difficult to cope with sexual changes. A standard consultation with a urologist-sexologist to discuss altered sexuality is considered preferable by the	During follow-up consultations, little attention is paid to the impact of treatment-induced sexual dysfunction on the relationship of men with prostate cancer and their partners.

Appendix one – Literature review and synthesis of the literature

						majority. Three months after treatment was the most suitable timing according to.	
Wood (2019)	USA	Cross-sectional	80 dyads	Social impact scale (SIS), functional assessment scale (FACT-P) and couple satisfaction index (CSI)	The study examined the relationship between of PCa stigma, QoL, and relationship satisfaction of PCa survivors and their spouses	Stigma had a negative association with QoL, but not relationship satisfaction. There were no significant demographic differences in regards to stigma	Implications for clinicians in regards to addressing PCa stigma with clients and areas for future research are discussed.
Mixed methods study							
O'shaugenessy (2013)	Mixed (Ireland, Australia, UK, USA)	Mixed method- Focus groups and couple interviews	4 focus groups (2 groups with men (n=5) and (n=5) and	Self-designed questionnaire based on the focus groups	To explore issues related to sexual function and relationships, for men and their	Qualitative research revealed 17 specific categories within three key themes:	Men are not able to clearly identify the challenges prostate cancer brings

Appendix one – Literature review and synthesis of the literature

		and online questionnaire	2 with spouses (n=7) and (n=9). Questionnaire 115 men and 35 partners		wives or partners, following diagnosis and treatment for prostate cancer.	sexual dysfunction, loss of libido and masculinity. The questionnaire found, that the majority of men had sufficient emotional and psycho-logical support. Predictors of loss of libido, erectile dysfunction and 'feeling less of a man' cancer having impacted on masculinity and distress during the last week	especially changes to their masculinity.
--	--	--------------------------	--	--	---	---	--

Appendix one – Literature review and synthesis of the literature

	Fergus (2011)	Docherty (2011)	Beck et al. (2013)	Nanton et al. (2010)	O'Shaughnessy (2015)	Oliffe (2015)	Sanders (2006)	Kelly et al. (2015)	Forbat (2012)	Nelson (2019)	Bamidele (2019)
CASP criteria (qualitative research)											
Global quality rating	8/10	5/10	8/10	3/10	5/10	6/10	5/10	8/10	8/10	7/10	10/10
Clear Aims?	Yes	yes	Yes	?	No	?	?	Yes	Yes	Yes	Yes
Qualitative methodology appropriate	Yes	yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Research design appropriate for address aims?	Yes	?	Yes	Yes	?	?	No	Yes	Yes	Yes	Yes
Appropriate recruitment strategy?	Yes	No	Yes	No	No	yes	No	No	Yes	No	Yes
Data collection appropriate?	?	Yes	yes	Not clear	?	Yes	Yes	Yes	Yes	Yes	Yes
Relationship between research and participants considered?	no	No	no	No	?	No	No	Yes	No	No	Yes

Appendix one – Literature review and synthesis of the literature

Ethical issues considered?	yes	?	?	Not clear	Yes	?	No	Yes	Yes	Yes	Yes
Data analysis sufficiently rigour?	Yes	No	yes	No	Yes	Yes	No	?	?	?	Yes
Clear statement of findings?	Yes	Yes	yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Valuable research?	yes	yes	yes	Yes	yes	yes	Yes	yes	Yes	yes	Yes

#### **4 - Summary of appraisal and CASP review**

The qualitative articles were appraised using the CASP tool and as two articles (Docherty et al. 2007; Oliffe et al. 2015) recruited their participants from cancer support groups. Such an approach may have resulted in the inclusion of couples that are more open for assistance and support and therefore this may have influenced their findings when compared to couples that were recruited from an oncology or hospital setting. Fergus (2011) purposively recruited couples that were well adjusted (according to the Dyadic Adjustment Scale), which may also have influenced the results and therefore may be less relevant for couples that are struggling with the consequences of a prostate cancer diagnosis and treatment. Nanton et al. (2010) performed a secondary analysis as several spouses attended and participated in the interviews of their husband. This study specifically focused on the role of the spouse in the process in order to create a model of partner activity in prostate cancer. Therefore this study did not include a couples' perspective when dealing with the consequences of prostate cancer. Sanders et al. (2006) did not provide any information or details as to how the focus group interviews were analysed, therefore it is difficult to determine how the findings were derived. Forbat et al. (2012) performed an ethnographic observation of 60 consultations with men and spouse and reported on the discussion of sexual consequences. This study therefore did not provide further detail or information how couples cope and adjust to the consequences of prostate cancer treatment.

## **APPENDIX TWO – ETHICAL APPROVAL DOCUMENTATION**

## Appendix two – Ethical approval documentation

### Local approval documentation

*original*

#### UNIVERSITY OF MALTA

#### UNIVERSITY RESEARCH ETHICS COMMITTEE

##### Check list to be included with UREC proposal form

Please make sure to tick ALL the items. Incomplete forms will not be accepted.

		YES	NOT APP.
1a.	Recruitment letter / Information sheet for subjects, in English	✓	
1b.	Recruitment letter / Information sheet for subjects, in Maltese		✓
2a	Consent form, in English, signed by supervisor, and including your contact details	✓	
2b	Consent form, in Maltese, signed by supervisor, and including your contact details		✓
3a	In the case of children or other vulnerable groups, consent forms for parents/ guardians, in English		✓
3b	In the case of children or other vulnerable groups, consent forms for parents/ guardians, in Maltese		✓
4a	Tests, questionnaires, interview or focus group questions, etc, in English	✓	
4b	Tests, questionnaires, interview or focus group questions, etc, in Maltese		
5a	Other institutional approval <i>for access to subjects</i> : Health Division, Directorate for Quality and Standards in Education, Department of Public Health, Curia...		✓
5b	Other institutional approval <i>for access to data</i> : Registrar, Data Protection Officer Health Division/Hospital, Directorate for Quality and Standards in Education, Department of Public Health...	✓	
5c	Approval from person <i>directly responsible for subjects</i> : Medical Consultants, Nursing Officers, Head of School...	✓	

Received by Faculty office on	
Discussed by Faculty Research Ethics Committee on	
Discussed by university Research Ethics Committee on	



## Appendix two – Ethical approval documentation

### UNIVERSITY OF MALTA

#### Request for Approval of Human Subjects Research

Please type. Handwritten forms will not be accepted

You may follow this format on separate sheets or use additional pages if necessary.

<p>FROM: <i>(name, address for correspondence)</i>                  Gerrit Albertus van Dijk,                  Department of Radiography, FHS University of                  Malta Msida, MSD2090, MALTA</p>	<p>PROJECT TITLE:                  Couples' experiences of prostate cancer                  treatment in Malta</p>
<p>TELEPHONE: (00356) 2340 1156</p>	
<p>E-MAIL                  gerbert.van-dijk@um.edu.mt</p>	
<p>COURSE AND YEAR:                  PhD student Cardiff University, Year 3</p>	
<p>DURATION OF ENTIRE PROJECT:                  from <u>October 2018</u> to <u>October 2019</u></p>	<p>FACULTY SUPERVISOR'S NAME:                  Dr Paul Bezzina</p>

ANTICIPATED FUNDING SOURCE:  
*(include grant or contract number if known)*

1. Please give a brief summary of the purpose of the research, in non-technical language.  
 A diagnosis of prostate cancer is a major life stressor that can disrupt the lifestyle and routine of couples. Along with the emotional and practical challenges that accompany the diagnosis and treatment of prostate cancer, the high rates of erectile, urinary and bowel dysfunctioning may cause an additional strain on the couples lives and routine. Although the physical and psychological consequences have been documented in the literature, less evidence is available regarding the impact of these changes on couples life and relationship. This current study will investigate the experiences of couples who have undergone prostate cancer treatment in Malta.

2. Give details of procedures that relate to subjects' participation  
 (a) How are subjects recruited? What inducement is offered? *(Append copy of letter or advertisement or poster, if any.)*  
 Participants will be purposively recruited from a regional oncology center in Malta. Patients who have been prescribed ADT and radiotherapy and are attending their follow-up appointment at the outpatient department will be asked to participate in this study. An allied health care professional (radiographer) has accepted to act as an intermediary (Appendix A). The intermediary will identify, approach and provide participant recruitment information packs (Appendix B) to potential eligible participants, using an agreed inclusion/exclusion criteria. This information pack will include an information leaflet and an expression of interest form, which the participants may complete and return to the researcher (using a FREEPOST envelope) if they are interested in taking part in the study. This will be followed by a telephone call from the researcher to provide additional information to interested participants, screen for suitability and answer any questions that they may have. A mutually convenient meeting will then be arranged to conduct interviews with those who agree to participate. This can take place in the local oncology

## Appendix two – Ethical approval documentation

(e) Which of the following data categories are collected?

Data that reveals – race or ethnic origin	YES / <input checked="" type="checkbox"/>
political opinions	YES / <input checked="" type="checkbox"/>
religious or philosophical beliefs	YES / <input checked="" type="checkbox"/>
trade union memberships	YES / <input checked="" type="checkbox"/>
health	<input checked="" type="checkbox"/> / NO
sex life	<input checked="" type="checkbox"/> / NO
genetic information	YES / <input checked="" type="checkbox"/>

3. How do you explain the research to subjects and obtain their informed consent to participate? (If in writing, append a copy of consent form.) If subjects are minors, mentally infirm, or otherwise not legally competent to consent to participation, how is their assent obtained and from whom is proxy consent obtained? How is it made clear to subjects that they can quit the study at any time?

Potential eligible participants will receive an information sheet from the intermediary which informs the participants about the study. Should the eligible participants be willing to participate they can return the expression of interest form (Appendix B) to the healthcare professional or send it back in the free post envelop. Prior the interview, participants will be fully informed and informed consent will be sought from each participant (Appendix D). Participants have the right to withdraw participation at any point in time without the need to provide an explanation and this will not affect their treatment or care.

4. Do subjects risk *any* harm—physical, psychological, legal, social—by participating in the research? Are the risks necessary? What safeguards do you take to minimize the risks?

Although there are no anticipated immediate risks for the participants in this study, in the process of sharing memories in the interview, there is a minor risk that participants may experience uncomfortable feelings about events and experiences. To minimise this risk, the interview will be paused or stopped if the participant is experiencing anxiety or distress as a result of the interview. The participant may then decide to continue with the interview or stop/withdraw/reschedule the interview. In addition, support from the local clinical psychologist has been sought and obtained (Appendix A) in order to be able to refer the participants should they wish to receive additional support.

## Appendix two – Ethical approval documentation

(b) Salient characteristics of subjects—number who will participate, age range, sex, institutional affiliation, other special criteria:

The following inclusion criteria have been formulated for men:

- Have a confirmed histology of prostate cancer
- Have consented to undergo external beam radiotherapy in conjunction with ADT.
- Need to be married and/or cohabiting with a partner / significant other
- Able to communicate in English
- At time of diagnosis, aged between 64 -74 years
- Have completed external beam radiotherapy treatment in the last 6-12 months

Exclusion criteria

(c) Describe how permission has been obtained from cooperating institution(s)—school, hospital, organization, prison, or other relevant organization. (*Append letters.*) Is the approval of another Research Ethics Committee required?

Since this study involves the collection of data from patients and their partner, and the student is register at Cardiff University, permission from Research and Ethics committee from Cardiff University and from the University of Malta Research Ethics Committee (UREC) will be sought. In order to able to recruit participants from the local oncology centre, permission has been sought and obtained from two clinical oncologist specialised in the management of prostate cancer treatment, the clinical chairperson of the Oncology and Heamatology Centre and quality and assurance manager (Appendix A). In addition, permission from the CEO and data protection officer of the local general hospital has

(d) What do subjects do, or what is done to them, or what information is gathered? (Append copies of instructions or tests or questionnaires.) How many times will observations, tests, etc., be conducted? How long will their participation take?

This study a semi structured interview schedule (Appendix C) based on the reviewed literature will guide the interview to explore associated issues. To obtain in-depth understanding of participants' experiences, responses will be probed and followed up when appropriate.

The men and their partners will be interview jointly as it will allow the partners to negotiate and construct their narrative (Racher 2003). Joint interviews enable individuals to blend their perspectives and present themselves as a couple (Hertz 1995). For this study, the couple is seen as a system that consists of two mutually influencing partners. The aim is to learn from the collective shared meaning attributed to the experience as partners and therefore a joint interview may provide an insight into the dynamics of the couple which would be harder to identify in one-to-one interviews. It is anticipated that interviews will last between 60-90 minutes.

Data will be digitally recorded and transcribed verbatim for data analysis. To analyse the data, the framework approach will be used.

## Appendix two – Ethical approval documentation

5. Are subjects deliberately deceived in *any* way? If so, what is the nature of the deception? Is it likely to be significant to subjects? Is there any other way to conduct the research that would not involve deception, and, if so, why have you not chosen that alternative? What explanation for the deception do you give to subjects following their participation?

No

6. How will participation in this research benefit subjects? If subjects will be “debriefed” or receive information about the research project following its conclusion, how do you ensure the educational value of the process? (*Include copies of any debriefing or educational materials*)

Although there are no immediate benefits for the participants, the results of this study could be used to improve local service provision.

## Appendix two – Ethical approval documentation

### TERMS AND CONDITIONS FOR APPROVAL IN TERMS OF THE DATA PROTECTION ACT

- Personal data shall only be collected and processed for the specific research purpose.
- The data shall be adequate, relevant and not excessive in relation to the processing purpose.
- All reasonable measures shall be taken to ensure the correctness of personal data.
- Personal data shall not be disclosed to third parties and may only be required by the University or the supervisor for verification purposes. All necessary measures shall be implemented to ensure confidentiality and, where possible, data shall be anonymised.
- Unless otherwise authorised by the University Research Ethics Committee, the researcher shall obtain the consent from the data subject (respondent) and provide him with the following information: The researcher's identity and habitual residence, the purpose of processing and the recipients to whom personal data may be disclosed. The data subject shall also be informed about his rights to access, rectify, and where applicable erase the data concerning him.

I, the undersigned hereby undertake to abide by the terms and conditions for approval as attached to this application.

I, the undersigned, also give my consent to the University of Malta's Research Ethics Committee to process my personal data for the purpose of evaluating my request and other matters related to this application. I also understand that, I can request in writing a copy of my personal information. I shall also request rectification, blocking or erasure of such personal data that has not been processed in accordance with the Act.

Signature:



#### APPLICANT'S SIGNATURE:

*I hereby declare that I will not start my research on human subjects before UREC approval*



DATE 01/06/2018

#### FACULTY SUPERVISOR'S SIGNATURE

I have reviewed this completed application and I am satisfied with the adequacy of the proposed research design and the protection of human subjects.



DATE 01/06/2018

***Return the completed application to your faculty Research Ethics Committee***

## Appendix two – Ethical approval documentation

*To be completed by Faculty Research Ethics Committee*

We have examined the above proposal and advise

**Acceptance**                      **Refusal**                      **Conditional acceptance**

For the following reason/s:

Signature \_\_\_\_\_ Date \_\_\_\_\_

*To be completed by University Research Ethics Committee*

We have examined the above proposal and grant

**Acceptance**                      **Refusal**                      **Conditional acceptance**

For the following reason/s:

Signature \_\_\_\_\_ Date \_\_\_\_\_

# Appendix two – Ethical approval documentation



## Participant consent form

**Title of study: Couples' experiences of prostate cancer treatment in Malta**

**Please initial box**

1. I confirm that I have read and understood the information sheet given to me regarding the above study. I have had the opportunity to consider the information, ask questions and have these answered satisfactorily.
2. I understand that I will take part in an audio-recorded interview and that my participation is voluntary and I am free to withdraw from the study at any time without giving a reason.
3. I understand that the information collected about me and the content of the recorded interviews will be handled in confidence, and that I will not be identifiable in any reports or publications of the research findings.
4. I understand that data gathered will be stored on the researcher work computer which is password protected and data will only be shared with the primary supervisors.
5. I understand that under the data protection act I have the right to access, rectify and where applicable erase the data concerning me.
6. I agree to participate in the above study and that the use of anonymised direct quotes obtained from the interview to be used in reports and publications relating to the research.

Name of participant.....Date.....

Signature.....

Contact Details:.....

Name of person taking consent.....Date.....

Signature .....

### Contacts for further information:

**Gerrit Albertus van Dijk** PhD Student

Department of Radiography, FHS  
University of Malta  
Msida, MSD2090, MALTA  
Tel: (00356) 2340 1156  
gerbert.van-dijk@um.edu.mt

**Dr Paul Bezzina**

Head of Department  
Department of Radiography, FHS  
University of Malta  
Msida, MSD2090, MALTA  
Tel: (00356) 2340 1824  
paul.bezzina@um.edu.mt

## Appendix two – Ethical approval documentation

original

FREC.FHS-1712-148



University of Malta  
Research Ethics and Data Protection  
Self-Assessment Form

### PART 1: INTRODUCTION

In line with the University of Malta's Research Ethics Review Procedures, if you are a University of Malta member of staff, student, or anyone else planning to carry out research under the auspices of the University, you must complete this form.

The first step is to read the University of Malta's Research Code of Practice and Research Ethics Review Procedures (both documents are available from <https://www.um.edu.mt/urec>) and make sure you understand them. Once you have done this, you should complete the self-assessment exercise that is contained in this form.

### PART 2: PRINCIPAL INVESTIGATOR AND RESEARCH PROJECT DETAILS

FROM: <i>(name, address for correspondence)</i> Gerrit Albertus van Dijk Department of Radiography, Faculty of Health Sciences, University of Malta Block A, Level 1, Room 67, Mater Dei Hospital, Msida, MSD2090, MALTA	TITLE OF RESEARCH PROJECT: Couples' experiences of prostate cancer treatment in Malta
TELEPHONE: 23401156	
EMAIL: gerbert.van-dijk@um.edu.mt	
STUDENT NUMBER: Cardiff University student	
COURSE AND YEAR: PhD year 3	
FACULTY/CENTRE/INSTITUTE/SCHOOL: FHS	
PROPOSED DATA COLLECTION START DATE: October 2018	SUPERVISOR'S NAME, EMAIL & TELEPHONE NUMBER: Please use University of Malta email address Dr Paul Bezzina paul.bezzina@um.edu.mt Tel: 00356 2340 1824
PROPOSED PROJECT END DATE: October 2019	

ANTICIPATED FUNDING SOURCE (if applicable):  
*(Include grant or contract number if known)*  
[Click here to enter text.](#)

Please give a brief summary of the purpose of the research, in non-technical language.

A diagnosis of prostate cancer is a major life stressor that can disrupt the lifestyle and routine of couples. Along with the emotional and practical challenges that accompany the diagnosis and treatment of prostate cancer, the high rates of erectile, urinary and bowel dysfunctioning may cause an additional strain on the couples lives and routine. Although the physical and psychological consequences have been documented in the literature, less evidence is available regarding the impact of these changes on couples life and relationship. This current study will



## Appendix two – Ethical approval documentation

investigate the experiences of couples who have undergone prostate cancer treatment in Malta.

### **PART 3: RESEARCH ETHICS AND DATA PROTECTION SELF-ASSESSMENT FORM**

Please consider your research proposal very carefully and check which sections are relevant in your case. If you are advised that you also need to complete Form B, this is available for download from <https://www.um.edu.mt/urec/notices/fullresearchproposalform>

Any breach of the Research Code of Practice or untruthful replies in this form will be considered a serious disciplinary matter.

**ANSWER ALL QUESTIONS IN THE SECTIONS THAT ARE RELEVANT TO YOUR RESEARCH**  
**All researchers to complete Section D**

Research that involves primary data collection from human participants or their tissues	Complete Section A
Research that involves primary data collection from animals* or their tissues *non-human vertebrates (including independently feeding larval forms and foetal forms of mammals as from the last third of their normal development) & cephalopods	Complete Section B
Research involves use of Secondary Data	Complete Section C
All research	Complete Section D
<b>NOTE:</b> <i>Primary data collection</i> - gathering information (data) directly (e.g., through measurement, observation, asking questions) for your research. <i>Secondary data</i> - using data already published or collected by somebody else	

## Appendix two – Ethical approval documentation

SECTION A   Research involving PRIMARY DATA from HUMAN PARTICIPANTS		YES or UNSURE	NO
A.1	Will your participants be harmed in any way?	<input type="checkbox"/> In addition to this form, you also need to fill in & submit Form B to your FREC. GO TO A.2	<input checked="" type="checkbox"/>  GO TO A.2
A.2	Are any of your research participants children, persons in institutions, persons with disability, victims of crime or abuse, substance abusers, or economically or educationally disadvantaged persons?	<input type="checkbox"/> In addition to this form, you also need to fill in & submit Form B to your FREC GO TO A.3	<input checked="" type="checkbox"/>  GO TO A.3
A.3	Are the participants in your research identifiable in some way? Choosing "No" means that all the data from your research are anonymous or have been anonymised and that there is little risk that the data can be de-anonymised and linked with identifiable individuals.	<input type="checkbox"/>  GO TO A.4	<input checked="" type="checkbox"/>  GO TO A.5

## Appendix two – Ethical approval documentation

SECTION A   PRIMARY DATA from HUMAN PARTICIPANTS continued		YES or UNSURE	NO
A.4	Do you plan to collect personal data which reveals race or ethnic origin, political opinions, religious or philosophical beliefs, membership of a trade union, health, sex life, sexual orientation, genetic data, or biometric data for the purpose of uniquely identifying a natural person?	x  In addition to this form, you also need to fill in & submit Form B to your FREC  GO TO A.5	[ ]  GO TO A.5
A.5	Do you plan to employ deliberate deception (actively providing false or misleading information or passively withholding information with the intention of misleading subjects about the research)? Note: Incomplete disclosure (providing general but accurate information to participants in order to avoid the potential for biased results) DOES NOT constitute deliberate deception in terms of this question.	[ ]  In addition to this form, you also need to fill in & submit Form B to your FREC  GO TO A.6	x  GO TO A.6
A.6	Do you need permission from a cooperating institution(s), school, hospital, organization, prison, or other relevant organization or another ethics committee?	x  In addition to this form, you also need to fill in & submit Form B to your FREC.  GO TO NEXT RELEVANT SECTION	[ ]  GO TO NEXT RELEVANT SECTION

### SECTION B | Research involving PRIMARY DATA from ANIMALS

Note: For the purposes of this section “animals” means non-human vertebrates (including independently feeding larval forms and foetal forms of mammals as from the last third of their normal development) & cephalopods.

B.1	Are you working with dead or live animals?	<b>If dead</b> GO TO B.4	<b>If alive</b> GO TO B.2
B.2	Will the animals in your research be harmed*?  *killed or cause the animal a level of pain, suffering, distress or lasting harm equivalent to, or higher than, that caused by the introduction of a needle in accordance with good veterinary practice.	<b>YES or UNSURE</b> [ ]  Complete the rest of this form and seek advice from your FREC. GO TO B.3	<b>NO</b> [ ]  GO TO B.3
B.3	Will the animals remain in their natural habitat in the course of your research?	<b>YES</b> [ ]  You may stop filling in this section and GO TO NEXT RELEVANT SECTION	<b>NO or UNSURE</b> [ ]  GO TO B.4
B.4	Will the animals be acquired legally <sup>1</sup> or from a legal source <sup>2</sup> ? <sup>1</sup> If working with protected species, all necessary permits need to have been obtained. <sup>2</sup> Legal sources may be licensed commercial outlets, donations by persons or institutions who have themselves obtained the animals legally and who are authorised to donate them.	<b>YES</b> [ ]  GO TO NEXT RELEVANT SECTION	<b>NO or UNSURE</b> [ ]  Complete the rest of this form and seek advice from your FREC

## Appendix two – Ethical approval documentation

SECTION C   To be completed by those collecting SECONDARY DATA		YES	NO or UNSURE
C.1	Have the secondary data you are going to use been published?	<input type="checkbox"/> GO TO SECTION D	<input type="checkbox"/> GO TO C.2
C.2	Do you have the written permission of the owner of the data that you may use the data for your research?	<input type="checkbox"/> GO TO C.3	<input type="checkbox"/> Complete the rest of this form and seek advice from your FREC
C.3	Have the data you are going to use been collected from human participants?	<input type="checkbox"/> GO TO C.4	<input type="checkbox"/> GO TO SECTION D
C.4	Have you obtained a copy of the consent form signed by the participants where secondary use, communication and subsequent sharing of data collected is expressly provided for?	<input type="checkbox"/> GO TO SECTION D Consent forms need to be sent to FREC before data collection starts with the other research materials as per Note 1 on page 5	<input type="checkbox"/> Complete the rest of this form and seek advice from your FREC

SECTION D   TO BE COMPLETED BY ALL		YES or UNSURE	NO
D.1	Is there significant foreseeable risk that your research can cause physical or psychological harm to people or harm to the environment or be misused by terrorists or military organisations?	<input type="checkbox"/> In addition to this form, you also need to fill in & submit Form B to your FREC GO TO D.2	x GO TO D.2
D.2	Is there any conflict of interest - financial or non-financial - that could benefit you or a relative or friend or business associate?	<input type="checkbox"/> In addition to this form, you also need to fill in & submit Form B to your FREC GO TO D.3	x GO TO D.3
D.3	Is there significant foreseeable risk to you as the principal investigator?	<input type="checkbox"/> Complete the rest of this form and seek advice from your FREC	x GO TO D.4
D.4	Is there any aspect of the proposed research which might bring the University of Malta into disrepute?	<input type="checkbox"/> Complete the rest of this form and fill in & submit Form B to your FREC	x Sign this form, ask your supervisor to sign it (if applicable), and submit to your FREC for filing. <b>YOUR RESEARCH NEEDS NO FURTHER APPROVAL HOWEVER SEE NOTE 1 BELOW<sup>1</sup></b>

## Appendix two – Ethical approval documentation

<sup>1</sup>NOTE 1: BEFORE STARTING DATA COLLECTION, copies of relevant research materials, including research proposal, consent forms (if used), copies of research materials such as questionnaires, discussion guides, stimuli, etc. need to be submitted to FREC for filing and audit purposes.

<p><b>PRINCIPAL INVESTIGATOR:</b> <i>I hereby confirm that I have read and understood the University of Malta Research Code of Practice and the University of Malta Research Ethics Review Procedures and further declare that the information provided above is truthful.</i></p> <div style="border: 1px solid black; height: 40px; width: 100%;"></div> <p>Copy of Signature may be pasted in here</p> <p>SIGNATURE PRINCIPAL INVESTIGATOR</p> <p>DATE Insert Date Here 01/06/2018</p>	<p><b>SUPERVISOR</b> <i>I have reviewed the research proposal and hereby confirm that it abides by the University of Malta Research Code of Practice and that the answers to the questions above reflect the contents of the research proposal.</i></p> <div style="border: 1px solid black; height: 40px; width: 100%;"></div> <p>Copy of Signature may be pasted in here</p> <p>SIGNATURE SUPERVISOR</p> <p>DATE Insert Date Here 01/06/2018</p>
---	--

Appendix two – Ethical approval documentation

original

FREC/FHS-1718\_148

**UNIVERSITY OF MALTA**

**UNIVERSITY RESEARCH ETHICS COMMITTEE**

**Check list to be included with UREC proposal form**

Please make sure to tick **ALL** the items. Incomplete forms will not be accepted.

		YES	NOT APP.
1a.	Recruitment letter / Information sheet for subjects, in English	✓	
1b.	Recruitment letter / Information sheet for subjects, in Maltese		✓
2a	Consent form, in English, signed by supervisor, and including your contact details	✓	
2b	Consent form, in Maltese, signed by supervisor, and including your contact details		✓
3a	In the case of children or other vulnerable groups, consent forms for parents/ guardians, in English		✓
3b	In the case of children or other vulnerable groups, consent forms for parents/ guardians, in Maltese		✓
4a	Tests, questionnaires, interview or focus group questions, etc, in English	✓	
4b	Tests, questionnaires, interview or focus group questions, etc, in Maltese		
5a	Other institutional approval <i>for access to subjects</i> : Health Division, Directorate for Quality and Standards in Education, Department of Public Health, Curia...		✓
5b	Other institutional approval <i>for access to data</i> : Registrar, Data Protection Officer Health Division/Hospital, Directorate for Quality and Standards in Education, Department of Public Health...	✓	
5c	Approval from person <i>directly responsible for subjects</i> : Medical Consultants, Nursing Officers, Head of School...	✓	

Received by Faculty office on	
Discussed by Faculty Research Ethics Committee on	
Discussed by university Research Ethics Committee on	

## Appendix two – Ethical approval documentation

### UNIVERSITY OF MALTA

#### Request for Approval of Human Subjects Research

Please type. Handwritten forms will not be accepted

You may follow this format on separate sheets or use additional pages if necessary.

FROM: <i>(name, address for correspondence)</i> Gerrit Albertus van Dijk, Department of Radiography, FHS University of Malta Msida, MSD2090, MALTA	PROJECT TITLE: Couples' experiences of prostate cancer treatment in Malta
TELEPHONE: (00356) 2340 1156	
E-MAIL gerbert.van-dijk@um.edu.mt	
COURSE AND YEAR: PhD student Cardiff University, Year 3	
DURATION OF ENTIRE PROJECT: from <u>October 2018</u> to <u>October 2019</u>	FACULTY SUPERVISOR'S NAME: Dr Paul Bezzina

ANTICIPATED FUNDING SOURCE:  
*(include grant or contract number if known)*

1. Please give a brief summary of the purpose of the research, in non-technical language.  
 A diagnosis of prostate cancer is a major life stressor that can disrupt the lifestyle and routine of couples. Along with the emotional and practical challenges that accompany the diagnosis and treatment of prostate cancer, the high rates of erectile, urinary and bowel dysfunctioning may cause an additional strain on the couples lives and routine. Although the physical and psychological consequences have been documented in the literature, less evidence is available regarding the impact of these changes on couples life and relationship. This current study will investigate the experiences of couples who have undergone prostate cancer treatment in Malta.

2. Give details of procedures that relate to subjects' participation  
 (a) How are subjects recruited? What inducement is offered? *(Append copy of letter or advertisement or poster, if any.)*

Participants will be purposively recruited from a regional oncology center in Malta. Patients who have been prescribed ADT and radiotherapy and are attending their follow-up appointment at the outpatient department will be asked to participate in this study. An allied health care professional (radiographer) has accepted to act as an intermediary (Appendix A). The intermediary will identify, approach and provide participant recruitment information packs (Appendix B) to potential eligible participants, using an agreed inclusion/exclusion criteria. This information pack will include an information leaflet and an expression of interest form, which the participants may complete and return to the researcher (using a FREEPOST envelop) if they are interested in taking part in the study. This will be followed by a telephone call from the researcher to provide additional information to interested participants, screen for suitability and answer any questions that they may have. A mutually convenient meeting will then be arranged to conduct interviews with those who agree to participate. This can take place in the local oncology.

## Appendix two – Ethical approval documentation

\* Missing information section 2a.

2. Give details of procedures that relate to subjects' participation

(a) How are subjects recruited? What inducement is offered? (*Append copy of letter or advertisement or poster, if any.*)

Participants will be purposively recruited from a regional oncology center in Malta. Patients who have been prescribed ADT and radiotherapy and are attending their follow-up appointment at the outpatient department will be asked to participate in this study. An allied health care professional (radiographer) has accepted to act as an intermediary (Appendix A). The intermediary will identify, approach and provide participant recruitment information packs (Appendix B) to potential eligible participants, using an agreed inclusion/exclusion criteria. This information pack will include an information leaflet and an expression of interest form, which the participants may complete and return to the researcher (using a FREEPOST envelop) if they are interested in taking part in the study. This will be followed by a telephone call from the researcher to provide additional information to interested participants, screen for suitability and answer any questions that they may have. A mutually convenient meeting will then be arranged to conduct interviews with those who agree to participate. This can take place in the local oncology centre, or at the participants' home. Written and verbal consent will be obtained prior each interview. No inducement is being given for participation in the study.



## Appendix two – Ethical approval documentation

(b) Salient characteristics of subjects—number who will participate, age range, sex, institutional affiliation, other special criteria:

The following inclusion criteria have been formulated for men:

- ? Have a confirmed histology of prostate cancer
- ? Have consented to undergo external beam radiotherapy in conjunction with ADT.
- ? Need to be married and/or cohabiting with a partner / significant other
- ? Able to communicate in English
- ? At time of diagnosis, aged between 64 -74 years
- ? Have completed external beam radiotherapy treatment in the last 6-12 months

Exclusion criteria

(c) Describe how permission has been obtained from cooperating institution(s)—school, hospital, organization, prison, or other relevant organization. (*Append letters.*) Is the approval of another Research Ethics Committee required?

Since this study involves the collection of data from patients and their partner, and the student is registered at Cardiff University, permission from Research and Ethics committee from Cardiff University and from the University of Malta Research Ethics Committee (UREC) will be sought. In order to able to recruit participants from the local oncology centre, permission has been sought and obtained from two clinical oncologists specialised in the management of prostate cancer treatment, the clinical chairperson of the Oncology and Heamatology Centre and quality and assurance manager (Appendix A). In addition, permission from the CEO and data protection officer of the local general

(d) What do subjects do, or what is done to them, or what information is gathered? (*Append copies of instructions or tests or questionnaires.*) How many times will observations, tests, etc., be conducted? How long will their participation take?

This study a semi structured interview schedule (Appendix C) based on the reviewed literature will guide the interview to explore associated issues. To obtain in-depth understanding of participants' experiences, responses will be probed and followed up when appropriate.

The men and their partners will be interview jointly as it will allow the partners to negotiate and construct their narrative (Racher 2003). Joint interviews enable individuals to blend their perspectives and present themselves as a couple (Hertz 1995). For this study, the couple is seen as a system that consists of two mutually influencing partners. The aim is to learn from the collective shared meaning attributed to the experience as partners and therefore a joint interview may provide an insight into the dynamics of the couple which would be harder to identify in one-to-one interviews. It is anticipated that interviews will last between 60-90 minutes.

Data will be audio recorded and transcribed verbatim for data analysis. To analyse the data, the framework approach will be used.

## Appendix two – Ethical approval documentation

\* Missing information 2b, 2c

2 (b) Salient characteristics of subjects—number who will participate, age range, sex, institutional affiliation, other special criteria:

The following inclusion criteria have been formulated for men:

- Have a confirmed histology of prostate cancer
- Have consented to undergo external beam radiotherapy in conjunction with ADT.
- Need to be married and/or cohabiting with a partner / significant other
- Able to communicate in English
- At time of diagnosis, aged between 64 -74 years
- Have completed external beam radiotherapy treatment in the last 6-12 months

Exclusion criteria

- Have been diagnosed with advanced disease which has spread beyond the prostate.
- Cannot identify partner/significant other
- Have completed external beam radiotherapy treatment more than 12 months
- Unable to provide informed consent

The partner should be able to communicate in English and provide informed consent. However, no further restrictions have been set as to not further limit the potential number of participants. Although Malta which has two official languages Maltese and English, data will be collected in English as the researcher is not fluent in Maltese and therefore cannot collect such data. Data will be audio recorded and transcribed verbatim for data analysis. To ensure pseudonymity, names will be replaced by a sequential identification code, which also indicates whether it involves participants are patients (P) or significant others (SO). Data will be stored separately from any codes and personal data to ensure confidentiality on the researcher home computer which is password protected and data will only be shared with the primary supervisors and examiners. Once the study is completed the data will be erased.

2 (c) Describe how permission has been obtained from cooperating institution(s)—school, hospital, organization, prison, or other relevant organization. (*Append letters.*) Is the approval of another Research Ethics Committee required?

Since this study involves the collection of data from patients and their partner, and the student is registered at Cardiff University, permission from Research and Ethics committee from Cardiff University and from the University of Malta Research Ethics Committee (UREC) will be sought. In order to able to recruit participants from the local oncology centre, permission has been sought and obtained from two clinical oncologists specialised in the management of prostate cancer treatment, the clinical chairperson of the Oncology and Heamatology Centre and quality and assurance manager (Appendix A). In addition, permission from the CEO and data protection officer of the local general hospital has been sought and obtained (Appendix A).

## Appendix two – Ethical approval documentation

(e) Which of the following data categories are collected?

Data that reveals – race or ethnic origin	YES / <input checked="" type="checkbox"/> NO
political opinions	YES / <input checked="" type="checkbox"/> NO
religious or philosophical beliefs	YES / <input checked="" type="checkbox"/> NO
trade union memberships	YES / <input checked="" type="checkbox"/> NO
health	<input checked="" type="checkbox"/> YES / NO
sex life	<input checked="" type="checkbox"/> YES / NO
genetic information	YES / <input checked="" type="checkbox"/> NO

3. How do you explain the research to subjects and obtain their informed consent to participate? (If in writing, append a copy of consent form.) If subjects are minors, mentally infirm, or otherwise not legally competent to consent to participation, how is their assent obtained and from whom is proxy consent obtained? How is it made clear to subjects that they can quit the study at any time?

Potential eligible participants will receive an information sheet from the intermediary which informs the participants about the study. Should the eligible participants be willing to participate they can return the expression of interest form (Appendix B) to the healthcare professional or send it back in the free post envelop. Prior the interview, participants will be fully informed and informed consent will be sought from each participant (Appendix D). Participants have the right to withdraw participation at any point in time without the need to provide an explanation and this will not affect their treatment or care.

4 .Do subjects risk *any* harm—physical, psychological, legal, social—by participating in the research? Are the risks necessary? What safeguards do you take to minimize the risks?

Although there are no anticipated immediate risks for the participants in this study, in the process of sharing memories in the interview, there is a minor risk that participants may experience uncomfortable feelings about events and experiences. To minimise this risk, the interview will be paused or stopped if the participant is experiencing anxiety or distress as a result of the interview. The participant may then decide to continue with the interview or stop/withdraw/reschedule the interview. In addition, support from the local clinical psychologist has been sought and obtained (Appendix A) in order to be able to refer the participants should they wish to receive additional support.

## Appendix two – Ethical approval documentation

5. Are subjects deliberately deceived in *any* way? If so, what is the nature of the deception? Is it likely to be significant to subjects? Is there any other way to conduct the research that would not involve deception, and, if so, why have you not chosen that alternative? What explanation for the deception do you give to subjects following their participation?

No

6. How will participation in this research benefit subjects? If subjects will be “debriefed” or receive information about the research project following its conclusion, how do you ensure the educational value of the process? (*Include copies of any debriefing or educational materials*)

Although there are no immediate benefits for the participants, the results of this study could be used to improve local service provision.

## Appendix two – Ethical approval documentation

### TERMS AND CONDITIONS FOR APPROVAL IN TERMS OF THE DATA PROTECTION ACT

- Personal data shall only be collected and processed for the specific research purpose.
- The data shall be adequate, relevant and not excessive in relation to the processing purpose.
- All reasonable measures shall be taken to ensure the correctness of personal data.
- Personal data shall not be disclosed to third parties and may only be required by the University or the supervisor for verification purposes. All necessary measures shall be implemented to ensure confidentiality and, where possible, data shall be anonymised.
- Unless otherwise authorised by the University Research Ethics Committee, the researcher shall obtain the consent from the data subject (respondent) and provide him with the following information: The researcher's identity and habitual residence, the purpose of processing and the recipients to whom personal data may be disclosed. The data subject shall also be informed about his rights to access, rectify, and where applicable erase the data concerning him.

I, the undersigned hereby undertake to abide by the terms and conditions for approval as attached to this application.

I, the undersigned, also give my consent to the University of Malta's Research Ethics Committee to process my personal data for the purpose of evaluating my request and other matters related to this application. I also understand that, I can request in writing a copy of my personal information. I shall also request rectification, blocking or erasure of such personal data that has not been processed in accordance with the Act.

Signature:



#### APPLICANT'S SIGNATURE:

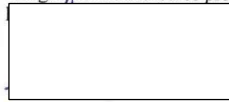
*I hereby declare that I will not start my research on human subjects before UREC approval*



DATE 27/6/2018

#### FACULTY SUPERVISOR'S SIGNATURE

I have reviewed this completed application and I am satisfied with the adequacy of the proposed research design and the measures proposed for the protection of



DATE 28/06/2018

***Return the completed application to your faculty Research Ethics Committee***



## Appendix two – Ethical approval documentation

### Consent form for intermediary person

Dear

I am a phd student at Cardiff university and as part of my study I am required to carry out a research study. The aim of my research is to investigate the experiences of couples undergoing prostate cancer treatment in Malta.

To be able to conduct this study, I would appreciate if you could act as the intermediary person for the data collection process. This process would involve the identification of potential eligible participants using an agreed inclusion and exclusion criteria (see attached) and to provide them with a participant's information sheet.

Dr Paul Bezzina is the local supervisor of my research project. Should you have any questions about the study feel free to contact me or my supervisor on the details below.

Thank you in advance.

Your sincerely

Gerrit Albertus van Dijk, PhD student

Department of Radiography, FHS

University of Malta

Msida, MSD2090, MALTA

Tel: (00356) 2340 1156

gerbert.van-dijk@um.edu.mt

Dr. Paul Bezzina, local supervisor

Head

Department of Radiography

University of Malta, MSD2090

Tel: (00356) 2340 1824

paul.bezzina@um.edu.mt

---

I accept to act as an intermediary person for this study

Department of Radiotherapy



## Appendix two – Ethical approval documentation

### Consent form psychological support

Dear

I am a phd student at Cardiff university and as part of my study I am required to carry out a research study. The aim of my research is to investigate the experiences of couples undergoing prostate cancer treatment in Malta.

Although there are no anticipated immediate risks for the participants in this study, in the process of sharing memories in the interview, there is a minor risk that participants may experience uncomfortable feelings about events and experiences. To minimize the risk, the interview will be managed in a sensitive manner and will be paused or stopped if the participant is experiencing anxiety or distress as a result of the interview. However should the participant require additional support, I am requesting to be able to refer participants to you should they wish to receive additional support.

Dr Paul Bezzina is the local supervisor of my research project. Should you have any questions about the study feel free to contact me or the local supervisor on the details below.

Thank you in advance.

Your sincerely

Gerrit Albertus van Dijk, PhD student

Department of Radiography. FHS

University of Malta

Msida, MSD2090, MALTA

Tel: (00356) 2340 1156

gerbert.van-dijk@um.edu.mt

Dr. Paul Bezzina, local supervisor

Head

Department of Radiography

University of Malta, MSD2090

Tel: (00356) 2340 1824

paul.bezzina@um.edu.mt

---

I accept to receive participants should they require additional support



Appendix two – Ethical approval documentation



Human Resources & Administration Directorate  
Administration Block, Room A210002  
Mater Dei Hospital  
Melita MSD 2050

Telephone: 2545 4137

DECLARATION BY VISITING STUDENTS

I hereby declare that I will respect the confidentiality and privacy of any personal data or information that I might come across during my attachment at Mater Dei Hospital and will in no circumstance disclose any such information. I also confirm that I am aware of the provisions of the Data Protection Act and that I will abide by all Government and hospital regulations related to data.

I am also aware that I will be assigned a mentor for the duration of my attachment and will abide by the directions given by the same mentor.

Details of student

Signature:

Full name:

ID number:

Educational Institution:

Date:

Gerit Alberus van Dijk.

54789 (A)

University of Malta

13/6/2018.

Endorsement by Parent/Guardian (where applicable)

Signature:

Full name:

ID number:

Date:

Disclaimer: Mater Dei Hospital will not be, under any circumstance, liable for consequential or incidental damages that might arise out of or related to the behaviour of the said student vis-à-vis the above instructions.

Data Protection Statement: The personal data supplied on this form will be processed in accordance with the Data Protection Act, XXXVI of 2001.

HRA/1043/01.0

Couples expenses of prostate cancer treatment in Malta.

INFORMATION MANAGEMENT  
&  
TECHNOLOGY DIRECTORATE  
MATER DEI HOSPITAL MSD 2090

13/06/2018

## Appendix two – Ethical approval documentation



Radiotherapy Department  
SAMOC

FORM : **Radiotherapy Proposal/Approval Audit/ Research purposes**

Document Code : RT-GeFO-P/A-001. Ver.01

Reference SOP : RT-Ge-PD.AP--001.Ver.01

### PROJECT TITLE: Couples' experiences of prostate cancer treatment in Malta

#### Introduction:

Prostate cancer is the most common diagnosed cancer in males in both Malta and Europe (Ferlay et al. 2013). Currently, almost five million European men are estimated to be alive with a diagnosis of prostate cancer, a number still increasing (Cremers, 2012). Although a large number of men are living with prostate cancer, these men report significant long term treatment consequences, which can negatively impact their quality of life (Elliott et al., 2011; Khan et al. 2011).

Along with the emotional and practical challenges that accompany the diagnosis and treatment of prostate cancer, the high rates of permanent erectile, urinary and bowel dysfunction can pose a significant challenge to men's psychological well-being (Berg et al. 2008). Although prostate cancer is unique to men, diagnosis and treatment can also negatively impact their partner (Galbraith et al. 2008). It has been suggested that psychological distress among female partners is higher than levels reported by patients (Chambers et al. 2013). Furthermore, challenges in communication, role changes, changes in attitude and interruption in intimacy are also common (Galbraith et al. 2011, McCoy et al. 2013, O'Shaughnessy et al. 2013). A diagnosis of prostate cancer is a major life stressor that can disrupt the lifestyle and routine of couples (De Sousa et al. 2012).

Whilst the physical and psychological consequences of prostate cancer and its associated treatments have been documented, less evidence is available regarding men and spouse's perceptions about the impact of these on their lives. Moreover the areas in which they most require assistance is also limited (Hashine et al., 2014; Prabhu et al., 2014; van TolGeerdink et al., 2013; Waller and Pattison, 2013).

In the local setting the only available treatment option is external beam radiotherapy treatment. This treatment can be given in combination androgen deprivation therapy. The use of androgen deprivation therapy (ADT), which is given to reduce the level of testosterone,

Prepared By: Mr. Edward Falzon	Reviewed By: Ms. Dorothy Aquilina	Issue Date: 18/07/2016	Version 01
Approved By: Dr Stefan Laspina	Authority of Issue:	Revision Date: 18/07/2017	Page 1 of 7

## Appendix two – Ethical approval documentation



Radiotherapy Department  
SAMOC

FORM :	<b>Radiotherapy Proposal/Approval Audit/ Research purposes</b>
Document Code : RT-GeFO-P/A-001. Ver.01	Reference SOP : RT-Ge-PD.AP--001.Ver.01

has been indicated to cause the greatest treatment related consequences (Walker, 2010). The European Association of Urology recommends the use of ADT for intermediate and high risk patient in combination with radiotherapy (Heidenreich et al. 2014). For intermediate risk patients a short term course of 4-6 months is recommended and long term ADT (2-3 years) is recommended for high risk patients (Heidenreich et al. 2014). Several long term treatment consequences have been reported for men undergoing ADT, such as depression (Watts et al. 2014) and a reduction in their quality of life (Saini et al. 2013). Men on ADT have reported as being more sensitive or sentimental, more irritable and angry and becoming more tearful (Donovan et al. 2015). Furthermore, the use of ADT can result in a range of negative perception of body image such as weight gain, hot flushes, breast tenderness and/or genital shrinkage (Donovan et al. 2015). Therefore, men undergoing this treatment option, and their partners, are often at a greater risk of suffering from physical and psychological consequences as a result of this treatment. However, research which investigates couples experiences of undergoing ADT is limited.

The inclusion of patients and relatives in the care process has also been indicated in the local national cancer plan (Ministry for health 2017). The national cancer plan has been implemented to set out an integrated and comprehensive plan of action for the next five years in Malta (2017 – 2021). One of the fundamental guiding principles outlined in the updated plan is the participation of patients in the care process. It was highlighted that cancer services should be patient-centered and should take account of patients' families and carers views and preferences particularly those affecting their quality of life. No previous studies have been conducted in this particular patient group and therefore this study could provide an insight into the current situation and potentially identify areas which could be targeted to improve local services.

The time frame following the treatment of prostate cancer can impact on the physical and psychological functioning of couples (Ross et al. 2016; Galbraith 2008). When evaluating specific time frames, it appears that the 6-12 months post-treatment phase is an important period in the physical and mental adjustment to prostate cancer. For example Galbraith et al (2008) suggest that both men and their partner reported lowest scores in mental and

Prepared By:	Reviewed By:	Issue Date: 18/07/2016	Version 01
Approved By:	Authority of Issue:	Revision Date: 18/07/2017	Page 2 of 7

## Appendix two – Ethical approval documentation



<b>Radiotherapy Department SAMOC</b>
<b>FORM : Radiotherapy Proposal/Approval Audit/ Research purposes</b>
Document Code : RT-GeFO-P/A-001. Ver.01      Reference SOP : RT-Ge-PD.AP--001.Ver.01

physical health at 12 month post treatment phase. Whereas Ross et al. (2016) reported that men reported an improvement in physical and mental health at 6 and 12 months, however spouse scores did not follow the same trend and a further decline in physical health was noted at 6 months with little improvement at 12 months. Both these studies indicate that patient scores predicted partner scores, which could indicate the importance of dyadic adjustment to prostate cancer. In addition, the 6-12month time period appears to be an important time frame in the adjustment to prostate cancer. What is not clear, however, is why men and their partners reported these changes in their physical and mental health in this particular time frame and in what areas they would require additional support or assistance. In addition, in depth qualitative studies, which focus on this particular time frame, are limited, as most qualitative studies include large time frames in their research (e.g. between 6 months and 10 years post treatment).

Besides the time frame following initial treatment, another aspect identified in the literature review is the development life stage. Most studies do not take this into account and often include patient groups with a large age span (40-86 years). This wide range categorisation decreases the information available for age-specific issues that may affect this group (De Sousa et al. 2012, Harden et al. 2009). When evaluating specific age groups, this often include younger men (Chambers, 2008; Wittmann, 2015). However, this group does not represent the majority of men diagnosed with prostate cancer. In the local Maltese setting, anecdotal evidence indicates that the majority of men are diagnosed with prostate cancer in the 64-74 age groups and therefore will be the focus of this study.

Prepared By: <input type="text"/>	Reviewed By: <input type="text"/>	Issue Date: 18/07/2016	Version 01
Approved By: <input type="text"/>	Authority of Issue: <input type="text"/>	Revision Date: 18/07/2017	Page 3 of 7

## Appendix two – Ethical approval documentation



Radiotherapy Department  
SAMOC

FORM :	<b>Radiotherapy Proposal/Approval Audit/ Research purposes</b>
Document Code : RT-GeFO-P/A-001. Ver.01	Reference SOP : RT-Ge-PD.AP--001.Ver.01

### Aim/s:

The aim of the study is to investigate couples' experiences of prostate cancer in Malta. To investigate this, the following research questions have been formulated.

### Research questions:

What are the experiences of men undergoing Androgen Deprivation Therapy and radiotherapy for prostate cancer (age 64-74) and their partners in the first year post-treatment in Malta?

### Sub-question

How do men and their partner cope/adjust following androgen deprivation therapy and radiotherapy in Malta?

### Method

To investigate men and their partners' experience of undergoing prostate cancer treatment, participants will be purposively recruited from a regional oncology centre in Malta. An intermediary employed in the oncology centre will identify, approach and provide an participant recruitment information packs to potential eligible participants, using an agreed inclusion/exclusion criteria (see below). This information pack will include an information leaflet and an expression of interest form, which the participants can complete and return to the researcher (using a FREEPOST envelope) if they are interested in taking part in the study. This will be followed by a telephone call by the researcher to provide additional information to interested participants, screen for suitability and answer any further questions. A mutually convenient meeting will then be arranged to conduct interviews with those who agree to participate and a written and verbal consent will be obtained prior each interview.

The following inclusion criteria have been formulated for men:

- Have a confirmed histology of prostate cancer

Prepared By: [ ]	Reviewed By: [ ]	Issue Date: 18/07/2016	Version 01
Approved By: [ ]	Authority of Issue:	Revision Date: 18/07/2017	Page 4 of 7

## Appendix two – Ethical approval documentation



Radiotherapy Department  
SAMOC

FORM : **Radiotherapy Proposal/Approval Audit/ Research purposes**

Document Code : RT-GeFO-P/A-001. Ver.01

Reference SOP : RT-Ge-PD.AP--001.Ver.01

- Have consented to undergo external beam radiotherapy in conjunction with ADT.
- Need to be married and/or cohabiting with a partner / significant other
- Able to communicate in English
- At time of diagnosis, aged between 64 -74 years
- Have completed external beam radiotherapy treatment in the last 6-12 months

### Exclusion criteria

- Have been diagnosed with advanced disease which has spread beyond the prostate.
- Cannot identify partner/significant other
- Have completed external beam radiotherapy treatment more than 12 months
- Unable to provide informed consent

The partner should be able to communicate in English and provide informed consent. However, no further restrictions have been set as to not further limit the potential number of participants. It is anticipated that approximately 4-5 couples (i.e. 4-5 prostate patients and 4-5 partners) will be recruited into this study, which is consistent with a qualitative case study of this nature.

To investigate the meaning that couples attribute to the impact of prostate cancer on their life and relationship, data will be collected using interviews. Interviews can be used to explore the views, experiences and beliefs of individuals or groups on specific issues (Kvale 1996). As this current study explores the experience of couples living with prostate cancer treatment, individual interviews with each couple will be used as a data collection method. Interviews can be divided into three fundamental types: structured, unstructured and semi-structured. For this study, a semi structured approach interview will be adopted to provide some structure to the discussion but also to allow the participants to talk freely about their experiences of a prostate cancer diagnosis and treatment. The interview schedule will be developed based on the review of the literature and the research question(s) of the study.

Prepared By: [ ]	Reviewed By: [ ]	Issue Date: 18/07/2016	Version 01
Approved By: [ ]	Authority of Issue:	Revision Date: 18/07/2017	Page 5 of 7

## Appendix two – Ethical approval documentation



Radiotherapy Department  
SAMOC

FORM :	<b>Radiotherapy Proposal/Approval Audit/ Research purposes</b>		
Document Code :	RT-GeFO-P/A-001. Ver.01	Reference SOP :	RT-Ge-PD.AP--001.Ver.01

To obtain in-depth understanding of participants' experiences, responses will be followed up where appropriate during the interview process. To help ensure appropriateness and understandability, the interview schedule will be piloted at all stages of data collection on the first couple recruited into the study.

In a study of this nature, Interviews can be conducted with the individual or with the couple simultaneously. In joint interviews, individuals could be influenced by the presence of a spouse (Aquilino, 1993). In separate interviews, it has therefore been suggested that participants are more freely able to express their own individual views than when interviewed jointly. For this study, the couples will be interview jointly as it will allow the partners to negotiate and construct their narrative (Racher 2003). It has been suggested that joint interviews enable individuals to blend their perspectives and present themselves as a couple(Hertz 1995). For this study, the couple is seen as a system that consists of two mutually influencing partners. The aim is to learn from the collective shared meaning attributed to the experience of the couple and therefore a joint interview can provide an insight into the dynamics of the couple which would be harder to identify in one-to-one interviews. It is anticipated that each interview will last between 45-90 minutes.

Prepared By: [ ]	Reviewed By: [ ]	Issue Date: 18/07/2016	Version 01
Approved By: [ ]	Authority of Issue:	Revision Date: 18/07/2017	Page 6 of 7



Appendix two – Ethical approval documentation



**Radiotherapy Department  
SAMOC**

FORM : **Radiotherapy Proposal/Approval Audit/ Research purposes**  
 Document Code : RT-GeFO-P/A-001. Ver.01      Reference SOP : RT-Ge-PD.AP--001.Ver.01

**Clinical Consultant Oncologist/s:**  
 Name and Surname (in block letters) and Signature

23 May 2018

---



---



---

**Head of Section (Radiotherapy Department):**  
 Name, Surname and Section (in block letters) and Signature

---



---



---

**Clinical Chairperson:**  
 Name and Surname (in block letters) and Signature:

Dep  4/6/18

**Quality Assurance Manager:**  
 Name and Surname (in block letters) and Signature:

*Once approval is granted for the study/audit to be carried out at the Radiotherapy Department (SAMOC). Patient radiotherapy information can be accessible only by complying with the following data protection principles, which are set out in the Data Protection Act 2001. In summary these state that patient's data shall:*

- *Be obtained and processed fairly and lawfully and shall not be processed unless certain conditions are met. Therefore patient's information (including scans) should be made anonymous by an appointed radiotherapy staff (from the Head of section)*
- *Be obtained for a specified and lawful purpose and shall not be processed in any manner incompatible with that purpose.*
- *Be adequate, relevant and not excessive for those purposes(in the case of a study or audit).*
- *Be accurate and kept up to date.*
- *Not be kept longer than is necessary for that purpose*
- *Be processed in accordance with the data subject's rights.*
- *Be kept safe from unauthorised access, accidental loss or destruction.*
- *Not be transferred to any third party unlawfully.*

Prepared By:	Reviewed By:	Issue Date: 18/07/2016	Version 01
Approved By:	Authority of Issue:	Revision Date: 18/07/2017	Page 7 of 7



## Appendix two – Ethical approval documentation



Radiotherapy Department  
SAMOC

FORM : **Radiotherapy Proposal/Approval Audit/ Research purposes**

Document Code : RT-GeFO-P/A-001. Ver.01

Reference SOP : RT-Ge-PD.AP--001.Ver.01

**Clinical Consultant Oncologist/s:**

Name and Surname (in block letters) and Signature


**Head of Section (Radiotherapy Department):**

Name, Surname and Section (in block letters) and Signature


**Clinical Chairperson:**

Name and Surname (in block letters) and Signature:

--

**Quality Assurance Manager:**

Name and Surname (in block letters) and Signature:

Once approval is granted for the study/audit to be carried out at the Radiotherapy Department (SAMOC). Patient radiotherapy information can be accessible only by complying with the following data protection principles, which are set out in the Data Protection Act 2001. In summary these state that patient's data shall:

- Be obtained and processed fairly and lawfully and shall not be processed unless certain conditions are met. Therefore patient's information (including scans) should be made anonymous by an appointed radiotherapy staff (from the Head of section)
- Be obtained for a specified and lawful purpose and shall not be processed in any manner incompatible with that purpose.
- Be adequate, relevant and not excessive for those purposes (in the case of a study or audit).
- Be accurate and kept up to date.
- Not be kept longer than is necessary for that purpose
- Be processed in accordance with the data subject's rights.
- Be kept safe from unauthorised access, accidental loss or destruction.
- Not be transferred to any third party unlawfully.

Prepared By: <input style="width: 150px; height: 15px;" type="text"/>	Reviewed By: <input style="width: 150px; height: 15px;" type="text"/>	Issue Date: 18/07/2016	Version 01
Approved By: <input style="width: 150px; height: 15px;" type="text"/>	Authority of Issue:	Revision Date: 18/07/2017	Page 7 of 7

## Appendix two – Ethical approval documentation

/13/2018

University of Malta Mail - Permission to conduct a research study at SAMOC



L-Università  
ta' Malta

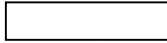
Gerbert van Dijk <gerbert.van-dijk@um.edu.mt>

### Permission to conduct a research study at SAMOC

2 messages

Gerbert van Dijk <gerbert.van-dijk@um.edu.mt>

13 June 2018 at 09:45



I am an assistant lecturer at the University of Malta (Department of Radiography) currently reading for a PhD at Cardiff University and as part of my studies, I am required to perform a research project.

The aim of my research study is to investigate the experiences of couples undergoing prostate cancer treatment. Data for this study will be collected through interviews with men and their partner following prostate cancer treatment. Participation in this study will be entirely on a voluntary basis.

In this regard, I am hereby asking for your approval to allow me to conduct this study amongst patients and their partner who willing to participate. All participants will be informed about the study by means of an information letter. Anonymity and confidentiality will be assured and maintained throughout the study and any data collected will solely be used for the purpose of this study. Kindly note that already have obtained approval and permission to conduct the study from the Oncology Department and the Data Protection Office (see attachment) and will be seeking approval from the University of Malta Research Ethics Committee.

While thanking you in anticipation for your assistance in the matter, I look forward for your favourable reply.

Yours sincerely,

Gerrit Albertus van Dijk, PhD Student

--  
Gerbert van Dijk  
Assistant lecturer

Department of Radiography, Faculty of Health Sciences, University of Malta  
Block A, Level 1, Room 67, Mater Dei Hospital, Msida, MSD2090, MALTA  
Tel: (00356) 2340 1156, email: gerbert.van-dijk@um.edu.mt

#### 3 attachments

SAMOC approval.pdf  
818K

DPO approval.pdf  
242K

Proposal gerbert 29052018.docx  
71K

13 June 2018 at 13:20

To: Gerbert van Dijk <gerbert.van-dijk@um.edu.mt>

Dear Mr van Dijk,

https://mail.google.com/mail/u/0/?ui=2&ik=e8ac5b605c&jsver=UgoiE7JEogo.en\_GB.&cbl=gmail\_fe\_180606.07\_p4&view=pt&search=inbox&th=163f8e0c271

## Appendix two – Ethical approval documentation

1/12/2018

University of Malta Mail - Permission to conduct a research study at SAMOC



L-Università  
ta' Malta

Gerbert van Dijk <gerbert.van-dijk@um.edu.mt>

### Permission to conduct a research study at SAMOC

Data Protection at M [redacted] 12 June 2018 at 13:16  
To: Gerbert van Dijk <gerbert.van-dijk@um.edu.mt>  
Cc: [redacted]

Dear Mr Dijk

On the basis of the documentation you submitted, from the MDH data protection point of view you have been cleared to proceed with your study provided that you obtain approval from MDH CEO.

Please contact [redacted] send a copy of your approvals and fill in the appropriate Data Protection Form. **This form should also be filled in by your primary supervisors given that data will be shared with them.**

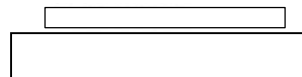
Remember that in no way should you retain any personal details you obtain from your research and this should be destroyed at the end of your study.

Extracted anonymised data from MDH applications must be carried out by MDH authorised personnel only.

You are requested to submit a copy of your findings to this office at the end of your study.

**NB: This email does not cover ethics approval.**

Regards



Mater Dei Hospital, Triq tal-Qroqq, Msida, Malta MSD 2090 | Tel +356 2545 0000 | www.mdh.gov.mt

Think before you print.

This email and any files transmitted with it are confidential, may be legally privileged and intended solely for the use of the individual or entity to whom they are addressed.

[https://mail.google.com/mail/u/0/?ui=2&ik=e8ac5b605c&jsver=UgoiE7JEogo.en\\_GB.&cbl=gmail\\_fe\\_180606.07\\_p4&view=pt&msg=163f3b6b5f2a1590&search=](https://mail.google.com/mail/u/0/?ui=2&ik=e8ac5b605c&jsver=UgoiE7JEogo.en_GB.&cbl=gmail_fe_180606.07_p4&view=pt&msg=163f3b6b5f2a1590&search=)

## Appendix two – Ethical approval documentation

/13/2018

University of Malta Mail - Permission to conduct a research study at SAMOC

I have no objection for you to proceed on the basis of documents you submitted. Please follow hospital policies regulating such activities.



Chief Executive Officer | teamMDH



Mater Dei Hospital, Triq tal-Qroqq, Msida, Malta MSD 2090 | Tel +356 2545 0000 | [www.careandcure.gov.mt](http://www.careandcure.gov.mt)

Think before you print.

This email and any files transmitted with it are confidential, may be legally privileged and intended solely for the use of the individual or entity to whom they are addressed.

**From:** Gerbert van Dijk [mailto:[gerbert.van-dijk@um.edu.mt](mailto:gerbert.van-dijk@um.edu.mt)]

**Sent:** 13 June 2018 09:46

**To:** 

**Subject:** Permission to conduct a research study at SAMOC

[Quoted text hidden]

[https://mail.google.com/mail/u/0/?ui=2&ik=e8ac5b605c&jsver=UgoiE7JEego.en\\_GB.&cbl=gmail\\_fe\\_180606.07\\_p4&view=pt&search=inbox&th=163f8e0c271](https://mail.google.com/mail/u/0/?ui=2&ik=e8ac5b605c&jsver=UgoiE7JEego.en_GB.&cbl=gmail_fe_180606.07_p4&view=pt&search=inbox&th=163f8e0c271)

## Appendix two – Ethical approval documentation

### Cardiff university approval

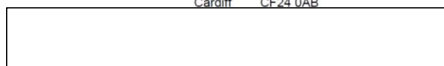
School of Healthcare Sciences  
Head of School and Dean Professor Heather  
Waterman

*Ysgol Gwyddorau Gofal Iechyd*  
*Pennaeth yr Ysgol a Deon Yr Athrawes Heather Waterman*



12 July 2018

Cardiff University  
Eastgate House  
13<sup>th</sup> Floor  
35 – 43 Newport Road  
Cardiff CF24 0AB



Prifysgol Caerdydd  
13<sup>ed</sup> Llawr  
Ty Eastgate  
35 – 43 Heol Casnewydd  
Caerdydd CF24 0AB

*Gerrit van Dijk*  
*Dept of Radiography*  
*Faculty of Health Sciences*  
*University of Malta*

Dear Gerrit

#### **Couples' experiences of prostate cancer treatment in Malta**

At its meeting of **10 July 2018**, the School's Research Ethics Committee considered your research proposal. The decision of the Committee is that your work should:

**Proceed subject to the resubmission and approval of minor amendments made by the Committee Chair.**

The Committee has asked that the lead reviewers' comments be passed onto you and your supervisor, please see attachment.

The proposal, amended in the light of the above points and in discussion with your supervisor, should be emailed to me for consideration by the committee Chair. You should email your response to [HCAREethics@cardiff.ac.uk](mailto:HCAREethics@cardiff.ac.uk)

When resubmitting your revised proposal you should provide a covering letter highlighting how and where you have amended the revised proposal, in the light of the above comments. You should clearly indicate the page number and line number/s, and you might find the following table a means of reporting the amendments you have made to the proposal. In addition, the changes should be highlighted in the revised documentation using the track changes facility.

*Cardiff University is a registered charity, no. 1136855*  
*Mae Prifysgol Caerdydd yn elusen gofrestredig, rhif 1136855*

## Appendix two – Ethical approval documentation

School of Healthcare Sciences  
Head of School and Dean Professor David Whittaker

*Ysgol Gwyddorau Gofal Iechyd*  
*Pennaeth yr Ysgol a Deon Yr Athrawes David Whittaker*



26 July 2018

Cardiff University  
Ty Dewi Sant  
Heath Park  
Cardiff CF14 4XN

Gerrit van Dijk  
University of Malta  
Department of Radiography



*Prifysgol Caerdydd*  
*Ty Dewi Sant*  
*Mynydd Bychan*  
*Caerdydd CF14 4XN*

Dear Gerrit

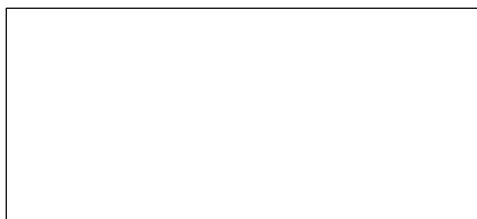
### **Couples' experiences of prostate cancer treatment in Malta**

I am writing to inform you that the Chair of the Research Ethics Committee has, following consultation, **approved** your revised research proposal. The Committee will ratify this decision at its meeting on *14 August 2018*.

Please note that if there are any major amendments to the project 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



*Cardiff University is a registered charity, no. 1136855*  
*Mae Prifysgol Caerdydd yn elusen gofrestredig, rhif 1136855*

## Approval of minor amendments

---

### Permission to conduct a research study at SAMOC

---

Gerbert van Dijk <gerbert.van-dijk@um.edu.mt>

11 March 2019 at 14:55

To: Data Protection at MDH

Cc:

To whom it may concern,

Following permission from MDH CEO and ethical clearance from the University of Malta I have been trying to recruit suitable participants from the oncology outpatients department. Unfortunately I have not been able to recruit suitable participants for my study and therefore I am requesting a change in the recruitment process. The current process involves the identification and recruitment of potential participants from the outpatients department by an intermediary. The proposed change involves the identification and recruitment of potential participant from the hospital IT system by an intermediary. All other aspects of this study will remain the same and I would like to ask if I would require any additional permissions/approvals from a data protection point of view.

Looking forward to hearing from you.

Regards,

Gerbert van Dijk

---

### Permission to conduct a research study at SAMOC

---

Caru

To: C

Cc: Y

11 March 2019 at 15:49

Dear Mr Van Dijk

As long as the changes in the methodology always involve an intermediary working at MDH aiding you to capture potential participants, you may proceed.

Thanks for your honesty.

Regards





## Appendix two – Ethical approval documentation

School of Healthcare Sciences  
Head of School and Dean Professor David Whittaker

*Ysgol Gwyddorau Gofal Iechyd*  
*Pennaethyr Ysgol a Deon Yr Athrawes David Whittaker*



1 November 2019

Cardiff University  
Ty Dewi Sant  
Heath Park  
Cardiff CF14 4XN

Gerrit van Dijk  
University of Malta  
Department of Radiography



*Prifysgol Caerdydd*  
*Ty Dewi Sant*  
*Mynydd Bychan*  
*Caerdydd CF14 4XN*

Dear Gerrit

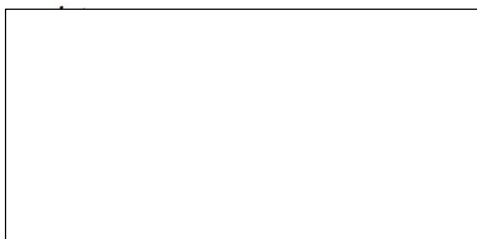
### **Couples' experiences of prostate cancer treatment in Malta**

I am writing to inform you that the Chair of the Research Ethics Committee has, following consultation, **approved** your minor amendment. The Committee will ratify this decision at its next meeting.

Please note that if there are any major amendments to the project 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



*Cardiff University is a registered charity, no. 1136855*  
*Mae Prifysgol Caerdydd yn elusengofrestredig, rhif 1136855*



## APPENDIX THREE – CONSENT FORMS

### Consent form example

**Participant consent form**

**Title of study: Couples' experiences of prostate cancer treatment in Malta**

**Please initial box**

I confirm that I have read and understood the information sheet given to me regarding the above study. I will be given a copy of the information leaflet to keep and I had the opportunity to consider the information, ask questions and have these answered satisfactorily.

I understand that I will take part in a 60-90 minute audio-recorded interview and that my participation is voluntary and I am free to withdraw from the study at any time without giving a reason.

I understand that the information collected about me and the content of the recorded interviews will be handled in confidence, and that I will not be identifiable in any reports or publications of the research findings.

I understand that data gathered will be stored on the researcher work computer which is password protected and data will only be shared with the primary supervisors and examiners.

I understand that as a participant, I have the right under the General Data Protection Regulation (GDPR) and national legislation to access, rectify, and where applicable ask for the data concerning me to be erased.

I agree to participate in the above study and that the use of anonymised direct quotes obtained from the interview to be used in reports and publications relating to the research.

Name of participant.....  ..... Date... 9/22/19 .....

Signature.....  .....

Contact Details:.....

Name of person taking consent..... *Selbach van Dyk* ..... Date... 22/8/2019 .....

Signature .....  .....

---

Couples' experiences of prostate cancer treatment in Malta information leaflet and consent form v02\_2018

## APPENDIX FOUR – DATA ANALYSIS

### Example of initial coding strategy with extract from Nvivo

41	29:48 8 - 29:55 4	I - You mentioned before that you noticed that you gained some weight?
42	29:55 3 - 31:15 9	P3 - Not a little bit, a lot I mean imagine buying shirts in September and in October I have to throw them away because this kept on growing and not because I am eating. I eat it's nothing out of the ordinary and I asked the oncologist whether this and they told me yes it could affect you because the hormones that you are receiving you are going to be like a woman in her menopause and one of the tendencies that they have is that they loose control of the growth of their stomach and it happens to me. Other things that I suffer that I experience is the hot flushes which are terrible because I hate he I hate summer and imaging the hot flushes they kill me. But I am used to them now but they happen
43	31:15 9 - 31:21 0	Were you aware that these changes could happen to you because of the treatment?
44	31:21 0 - 32:00 2	SO3 - yes and more they told he could have had more P3 - and thank God not all of them happened but I was fully aware what to expect SO3 - and more than once actually P3 - Yes first they brought me here to tell me and then they brought me here to explain what to tack and then before I had the marking for the again I was informed yes yes I was fully aware.
45	32:00 2 - 32:07 7	I - How do you feel now with all these changes?
46	32:07 7 - 32:52 4	SO3 - Bad P3 - I am not happy about them mainly the thing that bothered well there are two things that really bothered me as I said my tummy and my legs otherwise. Because I was always smart I like to look smart it was me.

CODE STRIPES

- urine side effects
- increase in weight
- hot flushes
- Bowel side effects
- positive changes
- negative changes
- Body image or manhood
- From HCP
- Negative

Coding Density

Code – increase in weight

## Appendix four – Data Analysis

41	29:48 .8 - 29:55 .4	I - You mentioned before that you noticed that you gained some weight?
42	29:55 .3 - 31:15 .9	P3 - Not a little bit, a lot I mean imagine buying shirts in September and in October I have to throw them away because this kept on growing and not because I am eating. I eat it's nothing out of the ordinary and I asked the oncologist whether this and they told me yes it could affect you because the hormones that you are receiving you are going to be like a woman in her menopause and one of the tendencies that they have is that they loose control of the growth of their stomach and it happens to me. Other things that I suffer that I experience is the hot flushes which are terrible because I hate he I hate summer and imaging the hot flushes they kill me. But I am used to them now but they happen
43	31:15 .9 - 31:21 .0	Were you aware that these changes could happen to you because of the treatment?
44	31:21 .0 - 32:00 .2	SO3 - yes and more they told he could have had more P3 - and thank God not all of them happened but I was fully aware what to expect SO3 - and more than once actually P3 - Yes first they brought me here to tell me and then they brought me here to explain what to tack and then before I had the marking for the again I was informed yes yes I was fully aware.
45	32:00 .2 - 32:07 .7	I - How do you feel now with all these changes?
46	32:07 .7 - 32:52 .4	SO3 - Bad P3 - I am not happy about them mainly the thing that bothered well there are two things that really bothered me as I said my tummy and my legs otherwise. Because I was always smart I like to look smart it was me.

CODE STRIPES

- urine side effects
- increase in weight
- hot flushes
- Bowel side effects
- positive changes
- negative changes
- Body image or manhood
- From HCP
- Negative

Coding Density

### Code – hot flushes

41	29:48 .8 - 29:55 .4	I - You mentioned before that you noticed that you gained some weight?
42	29:55 .3 - 31:15 .9	P3 - Not a little bit, a lot I mean imagine buying shirts in September and in October I have to throw them away because this kept on growing and not because I am eating. I eat it's nothing out of the ordinary and I asked the oncologist whether this and they told me yes it could affect you because the hormones that you are receiving you are going to be like a woman in her menopause and one of the tendencies that they have is that they loose control of the growth of their stomach and it happens to me. Other things that I suffer that I experience is the hot flushes which are terrible because I hate he I hate summer and imaging the hot flushes they kill me. But I am used to them now but they happen
43	31:15 .9 - 31:21 .0	Were you aware that these changes could happen to you because of the treatment?
44	31:21 .0 - 32:00 .2	SO3 - yes and more they told he could have had more P3 - and thank God not all of them happened but I was fully aware what to expect SO3 - and more than once actually P3 - Yes first they brought me here to tell me and then they brought me here to explain what to tack and then before I had the marking for the again I was informed yes yes I was fully aware.
45	32:00 .2 - 32:07 .7	I - How do you feel now with all these changes?
46	32:07 .7 - 32:52 .4	SO3 - Bad P3 - I am not happy about them mainly the thing that bothered well there are two things that really bothered me as I said my tummy and my legs otherwise. Because I was always smart I like to look smart it was me.

CODE STRIPES

- urine side effects
- increase in weight
- hot flushes
- Bowel side effects
- positive changes
- negative changes
- Body image or manhood
- From HCP
- Negative

Coding Density

### Code – body image/masculinity

## Appendix four – Data Analysis

41	29:48 8 - 29:55 4	I - You mentioned before that you noticed that you gained some weight?	
42	29:55 3 - 31:15 9	P3 - Not a little bit, a lot I mean imagine buying shirts in September and in October I have to throw them away because this kept on growing and not because I am eating. I eat it's nothing out of the ordinary and I asked the oncologist whether this and they told me yes it could affect you because the hormones that you are receiving you are going to be like a woman in her menopause and one of the tendencies that they have is that they loose control of the growth of their stomach and it happens to me. Other things that I suffer that I experience is the hot flushes which are terrible because I hate he I hate summer and imaging the hot flushes they kill me. But I am used to them now but they happen	<ul style="list-style-type: none"> <li>• urine side effects</li> <li>• increase in weight</li> <li>• hot flushes</li> <li>• Bowel side effects</li> <li>• positive changes</li> <li>• negative changes</li> <li>• Body image or manhood</li> </ul>
43	31:15 9 - 31:21 0	Were you aware that these changes could happen to you because of the treatment?	
44	31:21 0 - 32:00 2	SO3 - yes and more they told he could have had more P3 - and thank God not all of them happened but I was fully aware what to expect SO3 - and more than once actually P3 - Yes first they brought me here to tell me and then they brought me here to explain what to tack and then before I had the marking for the again I was informed yes I was fully aware.	<ul style="list-style-type: none"> <li>• From HCP</li> </ul>
45	32:00 2 - 32:07 7	I - How do you feel now with all these changes?	
46	32:07 7 - 32:52 4	SO3 - Bad P3 - I am not happy about them mainly the thing that bothered well there are two things that really bothered me as I said my tummy and my legs otherwise. Because I was always smart I like to look smart it was me.	<ul style="list-style-type: none"> <li>• Negative</li> </ul>

## Information provision – from HCP

41	29:48 8 - 29:55 4	I - You mentioned before that you noticed that you gained some weight?	
42	29:55 3 - 31:15 9	P3 - Not a little bit, a lot I mean imagine buying shirts in September and in October I have to throw them away because this kept on growing and not because I am eating. I eat it's nothing out of the ordinary and I asked the oncologist whether this and they told me yes it could affect you because the hormones that you are receiving you are going to be like a woman in her menopause and one of the tendencies that they have is that they loose control of the growth of their stomach and it happens to me. Other things that I suffer that I experience is the hot flushes which are terrible because I hate he I hate summer and imaging the hot flushes they kill me. But I am used to them now but they happen	<ul style="list-style-type: none"> <li>• urine side effects</li> <li>• increase in weight</li> <li>• hot flushes</li> <li>• Bowel side effects</li> <li>• positive changes</li> <li>• negative changes</li> <li>• Body image or manhood</li> </ul>
43	31:15 9 - 31:21 0	Were you aware that these changes could happen to you because of the treatment?	
44	31:21 0 - 32:00 2	SO3 - yes and more they told he could have had more P3 - and thank God not all of them happened but I was fully aware what to expect SO3 - and more than once actually P3 - Yes first they brought me here to tell me and then they brought me here to explain what to tack and then before I had the marking for the again I was informed yes yes I was fully aware.	<ul style="list-style-type: none"> <li>• From HCP</li> </ul>
45	32:00 2 - 32:07 7	I - How do you feel now with all these changes?	
46	32:07 7 - 32:52 4	SO3 - Bad P3 - I am not happy about them mainly the thing that bothered well there are two things that really bothered me as I said my tummy and my legs otherwise. Because I was always smart I like to look smart it was me.	<ul style="list-style-type: none"> <li>• Negative</li> </ul>

## Negative impact on emotions well being



## Appendix four – Data Analysis

### initial coding list – extracted from Nvivo

Name of code	Files	References
sexual Impact	12	36
gradual change	1	5
hope to recover from sexual impact	1	2
lack of detailed information	1	2
partner sexual needs	1	4
related to age	4	5
sexual aids or issues associated with them	7	16
Tests and examinations	9	10
Treatment decision	9	22
against HCP advice	1	1
in conjunction with close family and partner	2	3
no treatment decision or guided	3	8
reasoning for decision	5	5
wrong reasons	1	1
Body image or manhood	8	22
during awkward situation the man results to humour	2	2
getting it over and done	1	1
to downplay impact	6	8
Private Hospital appointment	7	10
Reasoning for private appointment	3	3
waiting time or delay	7	29
Helplessness	6	10
treatment goal vs side effects	6	10
information needs	5	14
follow doctors order	4	6
changes related to age	4	5
information seeking	4	10
Cancer Perception	2	2
cancer is death	1	2
cancer worry	1	2
common or normal disease	7	10
expect the worse and hope for the best approach	3	4
Family history	1	1
human being	1	2

## Appendix four – Data Analysis

Negative Perception	8	19
new reality	2	2
not mentioning cancer	3	3
Positive Perception	10	21
Rapid disease progression	5	10
the unknown	3	5
wrong perception	1	1
Health Seeking	3	6
Patient and HCP communication	3	4
Phone call	2	2
Provision of information	2	2
Disclosing cancer	3	13
benefit of disclosing	2	2
delayed disclosure	2	2
to close family or friends	7	8
Life style changes	3	3
diet changes	4	6
negative changes	6	23
positive changes	3	8
Relationship impact	2	2
negative changes	1	1
no changes or normal	3	4
positive changes	0	0
Partner impact	2	2
active information seeking	2	5
Actively encouraging to use aids to help sife effects	2	2
actively supporting husband by involving partner in activities	3	8
At a cost physical or psychological	7	11
Change in normal routine	3	3
do not want let him down	1	1
impact on work commitments	1	5
keeping strong appearance	2	2
Let partner make decision or choices and support these	1	1
not affected	1	1

## Appendix four – Data Analysis

notice emotional impact - more nervous	1	1
partner not involved	1	3
partner to keep record of patients	2	2
speaking to friend for support	1	5
taking control of disease	1	1
to get feedback from partner regarding health	6	11
willingness to make changes to life	1	1
worried about husband	6	10
man dealing with Pca	2	2
dealing on his own	3	9
downplay	4	7
impact of cancer on physical and psychological functioning	1	1
keeping healthy lifestyle	1	1
more worried about family than own health	1	1
Not wanting any information or details	1	1
unsupportive	2	4
Long lasting marriages	2	3
hope	2	2
busy clinic	2	2
positive treatment experience	2	2
impact on men	2	2
actively information seeking approach	1	2
continue work and social activities	1	2
difficulty to adapt to the changes	1	1
getting prepared or ready	2	3
health seeking	1	1
keeping emotions to himself	2	2
psychological impact	4	7
self conscious	1	1
sexual impact	1	1
feeling guilty to partner	1	1
hard to adapt to changes	1	1
worried about partner needs	1	1
social impact	1	1
still young to enjoy life	1	1

## Appendix four – Data Analysis

trying to help others	1	1
wanted further support	1	1
worried about physical health	1	1
social life impact	2	4
Emotional reaction	1	1
Negative	13	78
Positive	7	10
Physical complications	1	1
Coping	1	1
be positive	4	10
Compare to others	10	25
compare to pre-treatment self	4	9
compare to previous life struggles	3	4
Dealing it on your own	5	8
expecting cancer diagnosis	1	1
fighting cancer or disease	4	8
helping others	3	4
humour	7	15
keep a busy lifestyle	5	6
keep normal routine or life	9	36
living with cancer	1	1
not thinking about cancer approach	6	8
road to recovery	1	1
Radiotherapy treatment	1	1
description	6	14
negative	10	15
Positive	11	24
worried about causing delay for staff and patients	1	1
wrong perception	2	2
physical side effects	1	1
Bowel side effects	2	5
fatigue or tiredness	1	1
Hair loss	1	1
hot flushes	6	12
impact of side effects on other illnesses	1	1
increase in weight	6	11



## Appendix four – Data Analysis

infections	1	4
Loss of strength	6	13
perceived length or time of side effects	1	1
urine side effects	11	26
use of recorder mentioned	1	1
Couples coping	1	2
advantages and disadvantage of speaking to other patients	1	2
Family	1	1
impact on partner	1	1
individual and no couple coping	2	9
making positive changes as couple	2	2
Marriage strength	5	11
not talking about cancer	1	1
worried about accidents urinary of bowel	1	1
Communication	1	1
between couple	2	5
communication issues between HCP	3	10
Lack of communication	1	5
Working commitments	1	1
changes following medical treatment	1	1
long medical history	1	2
Change of doctor or handover	1	1
thinking about cancer or thought in your mind	1	2
Keep medical record or appointments	1	1
getting it done	1	1
bad experience	1	1
patient centred care	1	1
take it as it comes	1	1
outcome	1	1
out of your hands	1	1
individualised care	1	1
Early access to results through relative	1	1
issues with information given	1	2
issue with change in doctors	1	1
follow up	1	2

## Appendix four – Data Analysis

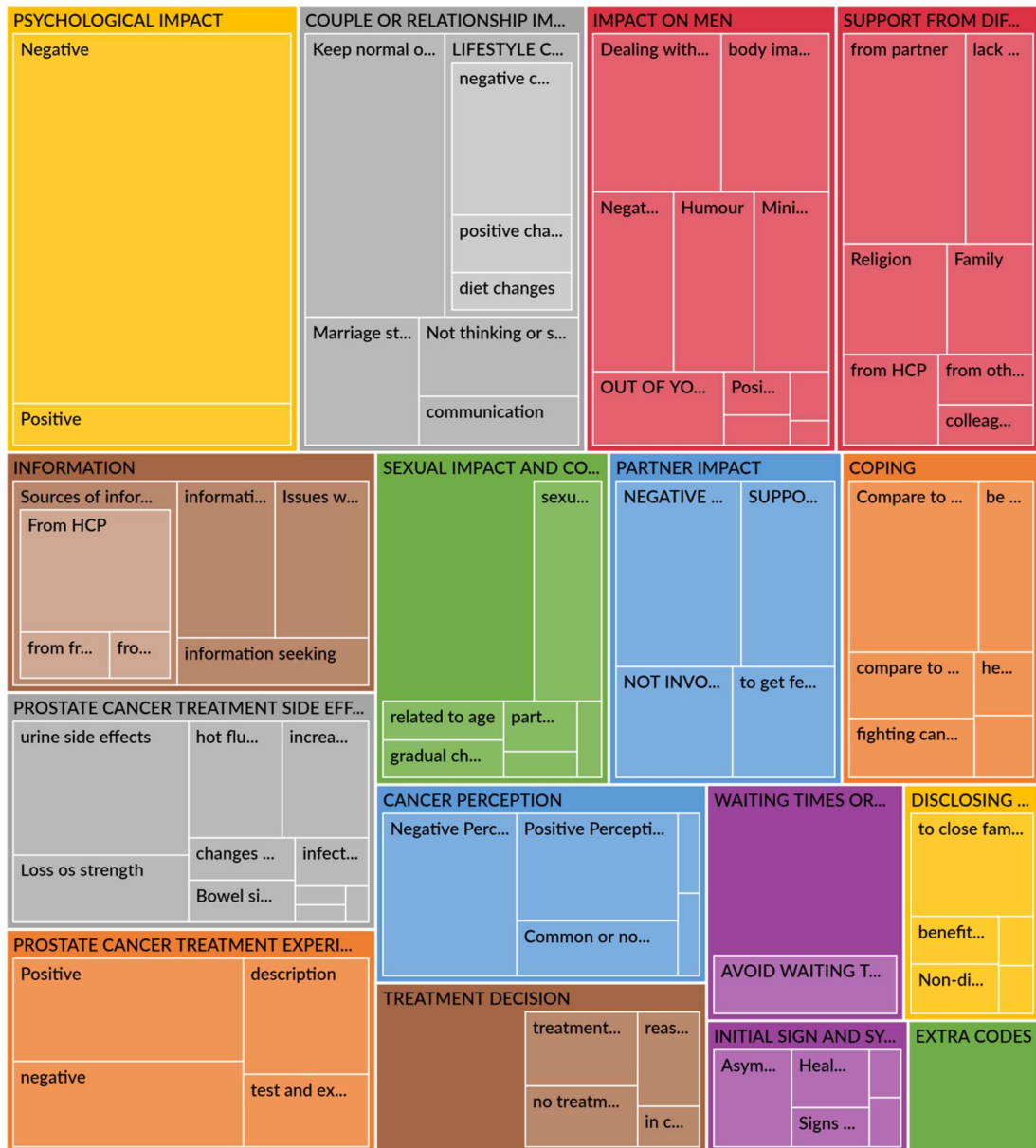
Initial Prostate signs and symptoms	0	0
Asymptomatic	7	10
Signs and symptoms	4	4
Symptom Progression	2	2
Diagnosis	0	0
Received from relative or friend	2	2
Provision of information	0	0
from friends or relatives	3	4
From HCP	8	14
from patients	3	4
incorrect information or lack of information	4	15
Written information	1	1
Support	0	0
colleagues or friends	3	4
Family	5	10
from HCP	6	9
from other cancer patients	4	5
from partner	7	27
lack of support or unsupportive	3	15
Religion	6	12
Cancer grief stages	0	0
anger	1	1
Grief	1	1
Initial shock	6	14



**Second framework – initial themes**

Name of initial theme	Files	References
SEXUAL IMPACT AND CONSEQUENCES	12	36
TREATMENT DECISION	9	23
WAITING TIMES OR TREATMENT DELAY	8	30
CANCER PERCEPTION	0	0
DISCLOSING CANCER DIAGNOSIS	0	0
COUPLE OR RELATIONSHIP IMPACT	0	0
PARTNER IMPACT	0	0
IMPACT ON MEN	0	0
COPING	0	0
PROSTATE CANCER TREATMENT EXPERIENCE	0	0
PROSTATE CANCER TREATMENT SIDE EFFECTS	0	0
INITIAL SIGN AND SYMPTOMS	0	0
INFORMATION	0	0
SUPPORT FROM DIFFERENT SOURCES	0	0
PSYCHOLOGICAL IMPACT	0	0

**Second framework – hierarchy chart**

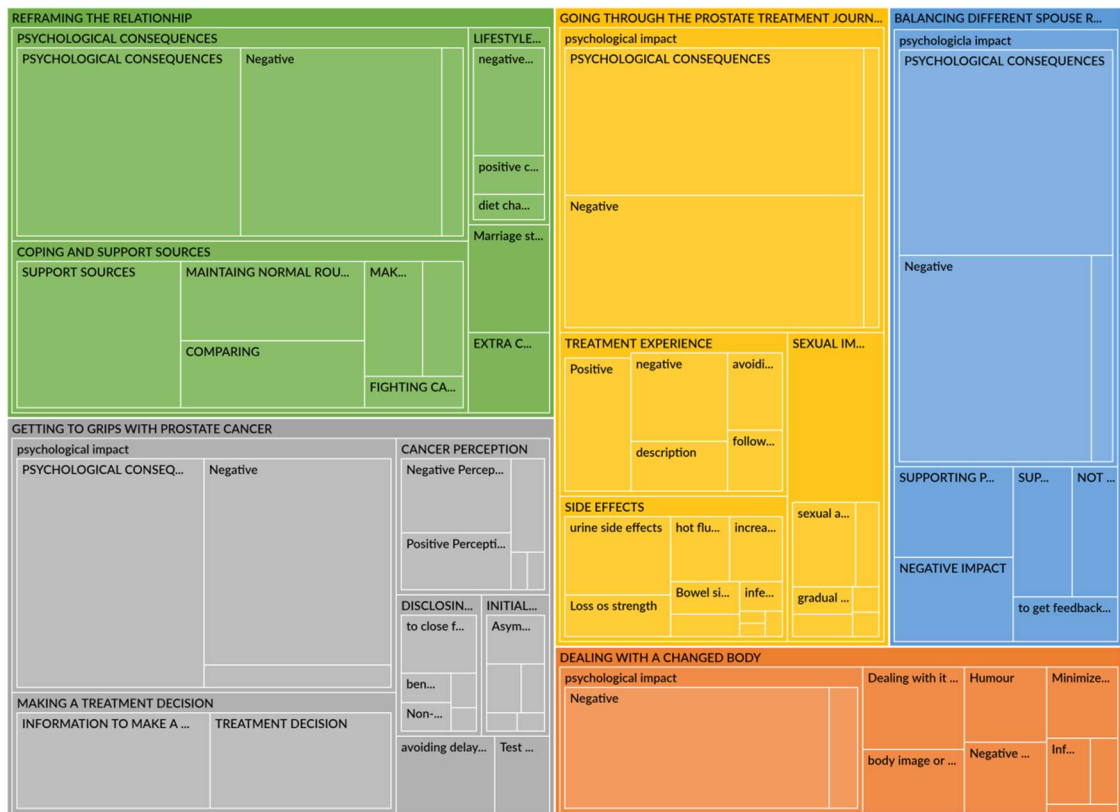


## Appendix four – Data Analysis

### Refining of themes

Name of themes	Files	References
REFRAMING THE RELATIONSHIP	0	0
GOING THROUGH THE PROSTATE TREATMENT JOURNEY	0	0
GETTING TO GRIPS WITH PROSTATE CANCER	0	0
DEALING WITH A CHANGED BODY	0	0
BALANCING DIFFERENT SPOUSE ROLES	1	1

### Refining of themes – hierarchy



## APPENDIX FIVE– RESEARCHER DIARY

### Research diary

June 10 2018

A local newspaper article entitle: Cancer survivors 'afraid to talk about emotions'. This newspaper articles describes a man who underwent cancer treatment and found it difficult to talk about his emotions:

*“The worst part of the cancer diagnosis was definitely after I survived,” the 60-year-old said. “The treatment took a lot out of me and I still felt like I could not put into words just how traumatic what had happened to me was.”*

*“Survivors are still afraid of talking about their emotions after they go through chemotherapy and a cancer diagnosis,” he said. Perhaps this was a side-effect of undergoing treatment, he admitted, adding that he was almost robotic when he was faced with the diagnosis.*

Another aspect that I found interesting and may also be relevant for my study is that this man mentioned that the worst part of the cancer diagnosis came after he survived the treatment. In particular the emotional impact of a diagnosis and treatment for cancer

*“I was always taught that I could not express what I felt, especially if I was afraid or in pain.*

January 2019

I have tried to recruit couples for my study over a total of period of weeks and only managed to recruit one couple into my study. Although prior to each follow-up session I met with the oncologist and reminded them about the

## Appendix five– Researcher diary

recruitment, it appears that only a limited number of couples are eligible and/or willing to participate in my study. As routine follow-up is scheduled at regular intervals (3-months, 6-months or yearly) it may be difficult to identify suitable candidates from the outpatients department. Subsequently a meeting was scheduled with the supervisory team to propose a new recruitment process that utilises the hospital management system to identify candidates that comply to my inclusion criteria.

May 5<sup>th</sup> 2019

An interesting article I found in a local news paper title: 'no sex please I am old'. This articles highlights the importance of remaining sexual active in particular at older age:

*'Rather than needing less sex, we need more intimacy and more sex in later life, as this informs the body that it is useful and happy, keeping us alive longer. There are other ways of achieving intimacy and happiness, but for a tried and tested method, you cannot beat sex'*

*Intimacy is all about allowing someone else to have privileges with our bodies, and communication is the best way to explore what those privileges are. Communication is the best foreplay. Mario Garrett was born in Malta and is currently a professor of gerontology at San Diego State University in California, US*

This article highlights the importance and potential benefit of remaining sexual active at older age, which may be negatively affected due to a prostate cancer treatment. Another aspect that this article suggest is the importance of communication in the process.



## Appendix five– Researcher diary

25<sup>th</sup> September 2019 – thought after interview

Patient was diagnosed with Ca prostate and was advised to undergo RT+hormone treatment due to his size as he was informed that more complications may arise from surgery in particularly urinary side effects such as incontinent. Patient was shocked when received the cancer diagnosis and this was due to a number of reason as he and his wife was passing through a hard time as she was just diagnosed with Alzheimer disease. In addition to this, his father was not doing so well and he had to take care of his father who was still living at home at that time.

If it was for him he would not have underwent any treatment at that time and let it into Gods' hand. However as he did not wanted to hurt his family or his wife he decided to go through the treatment. The man mentioned that the initial diagnosis was hard and that support from a psychologist or couple therapy could have been useful for them to prepare.

Treatment was hard in particular the preparation for RT treatment was not a nice experience. The man commented on the preparation for treatment in particular the bowel preparation with the enema was a concern for the patient as he needed to use the hospital facilities and these were not always in a good state. Besides the bowel preparation, the bladder preparation was sometimes difficult to maintain in particular during and after treatment. There were some episodes where the man could not hold his urine and had to abandon the treatment.

Side effects from RT and hormone included weight gain which the man noticed this as a result of his clothes. To ensure that the man was able to cope with the weight gain, the man was referred to the physiotherapy department for weekly session which helped him a lot. He mentioned that additional support for his partner would beneficial and that a psychologist could have prepared him better as he still had some concerns such as his erectile dysfunctioning and loss of libido and if this will continue after the hormone treatment?

## Appendix five– Researcher diary

Although the man was given and informed about the full list of potential side effects of treatment, being informed does not mean being prepared and he suggested that all men should have access to physiotherapy and psychological support as part of the treatment process.

January 2020 - Thoughts after interview transcribing

Initial thought during transcribing

- Long time for hospital appointments
- Can go for privately hospital to skip long queue
- Have relatives to assist in hospital appointments
- Hospital appointment not making sense as are before biopsy
- Patient was asked to make a decision regarding treatment
- Went to get information from previous patient
- Partner talks about we when discussing impact
- Had an impact on social life
- Suffer from hot flushes
- Suffers erectily side effects
- Expensive assistance medication (Viagra – 100 euro per month)
- Wanted more detailed explaining regarding sexual impact
- Needed to ask for details as opposed to be given information
- Gained weight as a result of hormone and finds this difficult to accept
- Partner provides support and fill in gaps during the interview although man is the main person who is speaking
- Suffered from sexual dysfunctioning
- Life goes on and couple needed to accept the changes
- Partner has been through cancer herself which helped
- Comparing to others who are worse
- Men sometimes get discouraged and partner needed to push him
- Had a lot of ups and downs in life and cancer was not a big deal
- Waited to long for action to be taken when PSA was high

## Appendix five– Researcher diary

- Traditional male approach do not let the cancer have an impact and try not to let it impact him
- Woman took an active post in supporting husband and push him
- Did not really discus the cancer or treatment with partner just continue their 'normal' life.
- Supportive partner
- Express love and affection in other ways such as hugging and kissing
- Partner not an active member of the conversation but help the husband to remember certain issues such as what side effects he experienced
- Treatment caused sexual side effects
- Brought them closer
- Compared to other which are worse
- Used Viagra but was not satisfied as the feeling is still not there only erection
- Partner was ok with terminating sexual activity
- Was initially refered for surgery however this was not possible
- Felt upset once received this news
- Made several changes before commencing treatment
- Took up certain activities (exercise once diagnosed)
- Lost a lot of weight before starting his treatment
- Wanted to get information from other prostate patients
- Went to see a doctor who underwent this procedure before

**January 2020 – initial codes and suggestions**

Content	Codes / suggestions
I - How did you realise something was wrong?	
<p>P4 - I realised nothing I am a diabetic and go to the policlinic and they take blood for diabetics every 6 months and once a year they take blood for more tests and it was in 2016 they told me they gave me a paper and go with this to mater dei to the reception.</p>	<p>Initial symptoms - No signs or symptoms</p> <p>Provision of information - lack of information provision</p>
I - So it was not something they were specifically looking for it was more an accidental finding?	
<p>P4 - No but at that time I received an appointment for March it was February and when I looked again it was not for March this year but for the next year. I had my Family doctor living right oposite of me and I asked him what did he think about it am I going to wait for this a whole year? They are saying that my blood is four. He told me that 4 is not very very bad what is your next time when you are taking blood and I told him in july and he said we will wait for your next test because I asked him if I should go private (healthcare)? Not to wait for all this time but he told me if I were you I would wait these next 6 months. And I waited for the next 6 months but then it went up until 9 and my doctor told me now no</p>	<p>Provision of Information– information needs (This perhaps more specifically relates to information seeking)</p> <p>Initial symptoms – symptom progression</p>
I - So this was after your checked for the second time your blood?	

Appendix five– Researcher diary

<p>p4- No but I had to come the year after the appointment they gave to me was for more than a year later 13 months later not the coming March of the 16 of March 17. But with the connection with my family doctor and now he said I will do what you told me last time I will go privately. I called DrX he was on Holiday during that period August/July and I went to him in September and he brought me to hospital and we started the procedure like that. It was not accidental cause they take blood and sometimes they only take for the diabetics and sometimes once a year they take it for the whole thing and from there they found out.</p>	<p>Treatment Delay – long waiting period</p> <p>Private hospital – avoid delay (Help seeking / treatment decision making???)</p> <p>Initial symptoms - Blood test done due to other medical condition</p>
<p>I - can you explain a bit in more detail what happened when you went to see Dr X</p>	
<p>P4 - Well I went to his clinic and he did me an ultrasound and directly he told me I believe you have a cancer and you need to come to hospital on the 20th but I told him that I have an appointment for March for the hospital of next year and he told me to forget about that and he gave me this new appointment and he made an appointment for a CT scan and a biopsy and when I came he said look I don't want this cancer to be the winner and I am going to make some more test a bonescan and an MRI and I asked him when? and he told me that he will put it in the computer and that they will call you. What I can only tell you is for your biopsy because these</p>	<p>Private hospital – change in general hospital appointment (Initial diagnosis / investigations???)</p> <p>Cancer perception – fight cancer</p>

Appendix five– Researcher diary

<p>are my people who will take of it and this was in September and he gave me an appointment for end of October. and I said I hope that everything will come through and the bone scan was done immediate as I have some relatives working in hospital my niece and I asked her if there is a chance that she can find out for me and she said for the CT scan it is not a problem because her husband works there and you can go on a Sunday when they don't have a lot of work and it took about a fortnite and I done it. But for the MRI there is no chance that I can get you in before</p>	<p>Treatment delay – avoid delay through hospital connections</p>
<p>P4 - But then after a fortnight she called and asked me if I wanted to be put on a list when someone misses their appointment? And I told he yes if you can call me at least an hour before the appointment I can make it to hospital. Than I think another month passed and she called me in the morning that I had to come the next morning at 8 in the morning. I had to be fasting for 5 hours and fortunately I was on a construction site and I was coming to hospital for the result of my rectal examination as we have rectal cancer in the family and I could join both appointments together. But then the hospital send me an appointment to see Dr X on the first November and my niece who works in the laboratory at the hospital told me that I am going there for nothing because you have your biopsy on the 28 and by 1st November your results will not be ready. she told me that she went to Urology and she made the appointment 8 days later to ensure that the results of the biopsy were ready and it happened. Dr X told me it is confirmed by</p>	<p>Treatment delay – avoid delay through hospital connections</p> <p>Prostate cancer diagnosis</p> <p>Cancer perception - Positive perception</p> <p>Provision of information – treatment options</p>

<p>the MRI and biopsy that you have an cancer it is not very  and its located in a good area and he explained about  the operation and I asked about the consequences of  such procedure and he said that it is near the valve of  the bladder and we might hit it we try not to hit it but  we might and I asked what will the consequences be and  he told me that if that happenend that you may need to  wear a diaper and he also explained the radiography and  he told me that you have to decide and he explained  more and he told me to think about it and that he will  get back to me in 1 month time for my decision. When I  went home I spoke to my neighbor who is also my friend  and he told me that I am not a specialist as I am a  general doctor but I will bring the results as I signed for  him to go through my history and all the test and he  gave me all the results and my doctor told me why don't  you speak to another doctor who was previously a  health minister and it was in the news when he was the  whip that he had prostate cancer and he went to  England for the surgery. We are not really friends  although we live in the same village and I made an  appointment with him and after the first minute I broke  the ice and told him that I wanted the advice from him  as a medical person and as an experienced person who  underwent this type of treatment. When I went to him I  gave him all my results and he asked under which doctor  I was and he told me that I am under good hands and  after I think half an hour he explained everything to me  and I asked him is there in England a better cure? He  told me listen you have nothing compare to what I had  Look I wanted hands that make 10 operations a week</p>	<p>Treatment decision – left  to the patient  Outcome of treatment /  side effects  Proposed treatment  option – Radiotherapy  Treatment decision left  in hand of the patient  information needs /  treatment decision-2<sup>nd</sup>  opinion (See earlier  point; I think this  perhaps forms the  basis of a more  meaningful theme that  relates to info  seeking/provision/need  s etc – in this case for a  specific purpose )  Information needs /  previous patient  experience</p>
--	--

Appendix five– Researcher diary

<p>not like in Malta where do maybe do 1 a month and I asked him if you were in my position what would you recommend? He told me if I were you I would go for radiography he told me that when he was a minister he changed these machines and then I was referred to Dr X for the radiography. Cause when I went back to mr X he told me now for the radiography you will not be under me anymore and he gave me two names and I choose one of them and then I started the radiography and I had to come here.</p>	<p>Advice from previous patient</p> <p>Cancer perception – positive perception</p> <p>Coping – compare to others</p> <p>Information needs - Advice from “expert” (doctor + previous patient)</p>
<p>I - Once you received your official diagnosis can you explain what your initial reactions were?</p>	
<p>P4 - hmm nothing ta  SO4 - Its part of life  P4 - It is part of life but I had to fight it I went to my field you know</p>	<p>Coping –mimizing impact/downplating</p> <p>Cancer perception –</p>



Appendix five– Researcher diary

<p>SO4 - life goes on I mean as long as the cancer is not like the other cancer that he has to lie down or that he feels hurt. I am hearing some friends having cancer some of them being in too much pain and we are lucky that he is not like that.</p> <p>P4 - It was September and in October I have my birthday and I like to celebrate my birthday you know. When we were here I told everyone about the prostate cancer who was here. I know I have to take care but not that big worries I am prepared now you have to be careful.</p>	<p>fight disease</p> <p>Coping - Comparing to other worse cancers</p>
<p>I - SO you mentioned that you have to fight it, what do you understand by that?</p>	
<p>P4- I have to fight it be prepared</p> <p>SO4- You have to find a solution you don't just want to sit down.</p> <p>P4 - my friend in the field start to tell me you have courage. but he died five months when I started radiotherapy cause I had something in my eye also everything at the same time two appointments. I told them the minor operation can you make me first because I have an appointment at the oncology hospital and both departments cooperated and worked together. And they told me 3 days ago philip of the field had a cancer like you but not in the prostate in the lung and you have to fight but there comes a time you cant fight anymore.</p>	<p>Cancer perception - Fight cancer (Does the 'fighting' perhaps fit within coping? Not giving up etc etc)</p> <p>Coping - Comparing to others (There also seems to be an element of social support here)</p>
<p>I - Can you described the reaction of your family and friends?</p>	

Appendix five– Researcher diary

<p>SO4- they are more upset than us much more upset</p> <p>P4 - my son he used to call everyday and asked if everything was alright. My friend one of my friends was with me on my birthday told me that this is something big. I mean I am not laughing I am honest but I am not crying that the world will finish now. At least until now 2 years have passed</p> <p>SO4- And I have heard that it is very common nowadays that prostate cancer is a normal sickness and that the improvements in science and health have improved that you are not going to die because of it.</p>	<p>Support – family</p> <p>Support – from friends</p> <p>(See previous comment – coping strategy?)</p> <p>Coping – common disease</p>
<p>I - So how would you say that the initial diagnoses have impacted on your life and relationship?</p>	
<p>P4 - Not much but when I was starting radiotherapy and was asking regarding the impact. I mean don't drink alcohol for now I mean you have to obey that wasn't the end of the world because after the 4 or 5 weeks if you take something I was a big drinker before.</p> <p>SO4- Normal a bit less of social life</p>	<p>Changes following prostate cancer – perceived negative</p> <p>Social impact</p>
<p>I- What do you mean with a bit less social life?</p>	
<p>P4 - What I mean is that the side effects have affected our social life. For example I cannot keep my urine and I have to run to make it to the toilet. Even when I am inside the car and driving I sometimes need to go to the bathroom and I have to stop and pee. Right now cause after the radiotherapy I took I don't know the name they</p>	<p>Social impact (Social activities have been affected due to the physical side effects in</p>

Appendix five– Researcher diary

<p>call it implant it is an injection every 12 weeks a big one and last time I visited here I think it was in May the</p> <p>Doctor saw me himself and not his assistant and he said very good and he stopped me before as I was supposed to take the last one in September but he stopped after 6 injections but he told me immediate that the side effects will going to remain for another year and even the radiotherapy. When I came for the last session it upset me a bit because they don't want me to eat vegetables because of the gas you have to drink a lot of water and unfortunately I have some problems in passing stools and my body was not coping with the changes in diet and they told me continue your normal life and if you have some gas will ask you to walk. It was a bit upsetting not the thing of having the cancer but the thing how it affected me and then they had a conversation with me after the treatment and they explained to me that the side effects will continue to increase for the next 7 weeks. And even with these injections I will need to be under the aircondition because I feel these hot rushes which they explained to me that you are going to be like a woman in menopause and really like 3 or 4 times I wake up at night with these hot flushes.</p>	<p>particular the urinary side effects)</p> <p>Physical side effects - Urine side effects (Social activities have been affected due to the physical side effects in particular the urinary side effects)</p> <p>Cancer perception – positive perception</p> <p>Changes following prostate cancer – negative (Social activities have been affected due to the physical side effects in particular the urinary side effects)</p>
---	--

Appendix five– Researcher diary

	<p>Psychological impact - Upset</p> <p>Physical side effects – hot flushes</p>
<p>I - So you already mentioned some but can you explain what side effects you experienced as a results of these treatments</p>	
<p>P4 - Well I mentioned to you before the urine side effects but the point is that I am not going that frequently but now our social life has affected for example if we are going to a restaurant I need to be sure where I can run to the toilet but it is getting better and even at home I told her not to lock the door because sometimes I get wet there is nothing to say about it but now I can keep it a bit more.</p>	<p>Physical impact - Urine side effects</p> <p>Social Impact</p>
<p>Where you aware of these side effects?</p>	
<p>P4 - Yes we were well informed. With my age and having been a diabetic for a long period I used to wake up around 3 times at night but then after I went up to 5 or 4 times at night.</p> <p>SO4 - but that was because you were drinking extra</p>	<p>Information provision - Well informed</p> <p>Coping – comparing to previous self</p>

Appendix five– Researcher diary

<p>water because of the treatment</p> <p>P4 - Yes because of the treatment I had to drink 3 cups of water in less than 5 minutes. because they explained to me aswell they want my rectum to be empty and they give me a small enema and then they want the bladder to be full and in that way one goes up and the other goes down so it will be more clear for them to give the treatment they explained everything what was happening. But they told me not only to drink before the treatment but during the whole day</p>	
<p>P4 - I mean I need to be well hydrated so that when I come here for treatment the water goes directly to the bladder.</p>	
<p>I - How would you describe your radiotherapy treatment? What was your experience?</p>	
<p>P4 - I mean the people were very nice once or twice I told them that I really needed to go to the bathroom and they told me that I was not full enough and they send me out as I had to drink again but they were very patient and very good. But after 10 sessions I started counting down because the water and stuff was making me upset I mean I tried to adapt to the changes but I got a bit more nervous my wife can tell you a bit more about this.</p>	<p>Treatment perception - Positive</p> <p>Psychological impact – nervous</p>
<p>How would you say that this treatment had an impact on your life?</p>	
<p>P4- Well I mean our relationship there is nothing to say about it and I have asked before and they told me that</p>	<p>Sexual impact</p>

Appendix five– Researcher diary

<p>after the treatment I may be able to perform again but until now there is still nothing</p>	
<p>I - Nothing?</p>	
<p>P4 - Well they try to give me some pills but they might have an impact on your heart in Maltese they call them Viagra but they use other names and to be honest I am a bit afraid to use them as he gave them to me for a month the smallest one but first of all it is too much expensive I mean 100 Euro for a month and even though I took it I did not find it was working very well and on the other side I was a bit afraid of using it because of the side effects of this treatment.</p>	<p>Sexual impact – use of sexual aids</p> <p>Sexual impact – concerned with sexual treatment side effects</p> <p>Sexual impact – cost associated with sexual treatment</p> <p>Sexual impact – effectiveness of treatment</p>
<p>I - did they give you any other options?</p>	
<p>P4 - Well when I spoke to a previous patient the one I spoke about beforehand he explained that there are options for example an injection in the penis but here they never mentioned it.</p>	<p>Provision of Information – information seeking previous patient</p> <p>Provision of information – sexual needs</p>
<p>I - did you ask about it?</p>	

Appendix five– Researcher diary

<p>P4 - Well once I asked a doctor but it doesn't help you it is you who has to decide I will come to it. You have to explain to me what the side effects are for example the side effects of the viagra it is another name that they use but when you read about the side effects you have to take care of your heart and I am very worried about that. And during when I was having these thing I am telling you I was more worried about my eyes than about my cancer I mean it has been almost all my life from 6 years on. I have made several operations and have made some implants and I was very worried because I had bad experiences from when I was a child and I was afraid that I was going to loose my eye sight.</p>	<p>Provision of information – information sexual needs</p> <p>Sexual impact - Concerned with use of sexual aids</p>
<p>I - So you mentioned that you received some information regarding the sexual side effects.</p>	
<p>P4 - Well I had to ask for it because when I asked they told me we have to discuss it and we will need to set-up another appointment with the doctor because not everybody will have the same dose it was like not like she was explaining something to me but more if she was teaching to students. I wanted more infromation for example the side effects of this is the same or more than viagra it doesn't affect your eyes. and I was going to make another appointment with that Dr who underwent this treatment but I am not sure to be honest.</p>	<p>Provision of information – lack of details from HCP</p> <p>(Was the HCP uncomfortable discussing sexual recovery with patient? Appears that HCP to refer patient to doctor or lack of knowledge?)</p>

Appendix five– Researcher diary

	<p>Provision of information – sexual information needs</p> <p>Provision of information – previous patient</p>
<p>I - Any reason why you haven't made the appointment yet?</p>	
<p>P4 - My wife wishes to I mean the thing is this I don't know to exactly explain myself but I will try. My age is I am going to be 71 in October If I did not have the prostate cancer I might have stayed how I was before of this treatment you know I don't know if I am going to do something that is for nothing or for something that would really help help without any greivous side effects I mean the side effects I wanted to be explained more I mean I have to ask for or they have to ask me? That is my question</p>	<p>Coping - Compare to prior treatment</p> <p>Sexual impact - Concerned with use of sexual aids</p> <p>Provision of information – sexual information needs</p> <p>(Have a think about how you organise info needs/issues when you start developing themes – do they all sit under one heading or do they (or some of them) relate to broader issues?)</p>



Appendix five– Researcher diary

<p>I - What do you think?</p>	
<p>P4 - They know my age, they know my wife is young well young 40 years hahah</p>	<p>Individual care - Man has young partner</p>
<p>I - so you think they should have given you the information?</p>	
<p>P4 - I think they should have given the information themselves not wait for me to ask them about the information.</p>	<p>Provision of information – pro-active vs reactive</p>
<p>P4 - the point is this 99 out of 100 may not have a young wife and they may think that the information they do not need to give due to my age. I think that they need to consider each case by themselves. I am not blaming them but its something that could be changed.</p>	<p>Individual care -</p>
<p>I - So looking back at your whole treatment what would like that should have been done differently?</p>	
<p>P4 - everything was good I mean all this stuff I mean even when I came early for the treatment they sometimes let me in before. My wife wants to take me by car so i asked if it is possible to come in the afternoon and then they usually arranged my timing. It was only on tuesday when i had to come in the morning because of the doctor appointment but they were very helpfull if I asked for 10 times they changed in 9 times. so they were very veryhelpfull.</p>	<p>Treatment experience - Positive</p>

Appendix five– Researcher diary

<p>I - how would describe your experience of your husband prostate cancer treatment?</p>	
<p>SO 4- I mean when you mention or when you hear cancer it is like death the end</p> <p>P4 - because she said because if the science and so on the wife of my brother was speaking to me that she had something myself and she had a cousin who also had prostate cancer and it had spread to the spine and he died do it is not something small. I mean there are two names I don't know they call it malignant or benign and the three doctors that saw me told me that your case it is still small it is still in the capsule but it is a little bit near your valve. But if you do nothing no operation and no radiography for the next few years you will be fine but then it will be too late.</p>	<p>Cancer perception – negative</p> <p>Coping - Compare to others (In relation to coping; have a think about why people compare themselves to others)</p> <p>Cancer perception - Positive</p>
<p>I - So you got a lot of information form others sources not just the hospital</p>	
<p>P4 - Yes as when I went to speak to Dr X he told me that I had to decide on the treatment and therefore I went to my GP and other sources. I mean at work I spoke to someone who also had this prostate anyway when I spoke to my GP he told me to go and speak to this Dr X as he is not only a doctor but he also was diagnosed and underwent treatment for prostate cancer</p>	<p>Information provision – multiple sources</p>
<p>I - So you could get his medical knowledge as well as his experience as a patient?</p>	

Appendix five– Researcher diary

<p>P4 - But then I decided to go for the radiotherapy</p>	
<p>I - What was the reason why you decided to go for the radiotherapy treatment?</p>	
<p>P4 - because it was near the valve of the bladder and that I may leak after and with this they told me that after the treatment I might have an erection again but I don't think that I will have it again. because I took the course of one month and I took once the 20 and once the 50 but no. I mean they cure you from the cancer but what about these things they do not tell you I mean I had to ask.</p>	<p>Treatment decision - Rationale Sexual impact - effectiveness of treatment Information provision - information needs</p>
<p>I - So what you are saying is that they inform you about the cancer treatment but do not explain about the impact of this treatment as you needed to ask to get this information?</p>	
<p>P4 - well when you ask something they will answer but limited and I wanted more details. SO4 - Maybe it is that nobody is asking so much questions</p>	<p>Provision of information - Information needs</p>
<p>I - So now I would like to ask some individual questions, how would you describe your personal reaction after this happened?</p>	
<p>SO 4 - Normal I would say</p>	<p>Coping – normal return to normal</p>

Appendix five– Researcher diary

	(Is this coping or emotional impact?)
I - normal in what way?	
SO 4 - Well once you got the sickness you got the sickness I mean it a matter how you will hear it I mean it is not then end of the day	Partner try to reduce impact? Coping mechanism?
I - So it is not the end?	
SO4 - And I always think that the Maltese are very lucky because they have a hospital where they can rely on I mean I came from a third world country and if you don't have money you will die because let's face it cancer is an expensive treatment and here in Malta I always said that when you have a cancer you have a fighting chance cause of the facilities available. I am worried about the he might feel pain or something like that. But I never it never crossed my mind and I searched a lot about prostate cancer online so I am not that worried and it appears to be a normal sickness for older guys.	Coping - Comparing to other healthcare settings  Psychological impact – worried Information seeking – online Information seeking to deal with psychological impact (Appears that partner dealt with prostate cancer by gathering information from internet )

Appendix five– Researcher diary

	Coping – normal
I - Do you think they look differently at cancer?	
SO4 - I think everywhere I mean cancer is a cancer and a lot of people will die and as I said science is improving so we have a fighting chance not like before. For example I have some relatives who died before because of cancer and she died of breast cancer.	Cancer perception –  Compare to others – worse
I - how would you say the diagnosis and treatment impacted on your life?	
SO4 - a bit of the social element and a bit of adjustment for example I cannot sleep properly at night because he has to wake up all the time and I have to ask if he is fine. I have to you know when I am driving I have to be patience with him as sometimes he is telling me to drive faster as he needs to go to the toilet you know. I have encouraged him to wear a diaper and I bought some for him but he is not very keen on using them but a bit of adjustment and we are not that kind of couple we want to enjoy our lives I think we are quite open minded about.	Social impact  Impact on partner – lack of sleep  Psychological impact – worried  Impact on partner – to be patient with husband  Support – from partner  Coping/adjusting - Couple willing to adjust life and lifestyle
I - So you made some adjustments	
SO4 - I mean small adjustments I mean everybody else I think that most people are too much focused on their	Support – couple

Appendix five– Researcher diary

<p>lives that they easily get upset when they have to make some changes but with us it is like easier we try our best but we are in this together.</p>	
<p>I - how would you describe his adjustment?</p>	
<p>SO4 - I would say he is not doing that bad he is losing sometimes his temper and that is mainly when he is having those hot flushes and that he can't go out that much as he liked to go out before for a drink or two.</p> <p>There are some times that he really gets annoyed I mean you cannot really do anything about it as he was taking some medication at that time as he is a diabetic. And we have to keep in mind that he is not getting any younger and I am expecting that so probably it may be a bit hard for him to adjust to all these things at the same time. For me it is like I am watching him and asking him if he is alright</p>	<p>Psychological impact – change in mood/temper</p> <p>Physical side effects – hot flushes</p> <p>Changes following prostate cancer – negative</p> <p>Changes following prostate cancer – linked to age</p> <p>Impact on partner- worried</p>
<p>I - How would you say that you support him?</p>	
<p>SO4 - I just let him do what he wants for example if he wants to drink this or do that I let him do it. I mean if he feels like eating this or drinking this as long as it is not every day I mean if it is once a week I mean just because you can drink a beer you don't have to drink 6 bottles. I am just here to remind him and to support him.</p>	<p>Support – from parner</p> <p>Wife to keep husband at bay but at same time let him free (Let him free</p>

Appendix five– Researcher diary

	and support/control partner – balance between autonomy of patient and support/dictate)
P4 - I mean I finished treatment just in March but I am still undergoing the implants but the side effects are still here with me	
I - So which of these side effects would bother you the most?	
<p>P4- I would say the hot flushed and the going to the bathroom and then there are the effects of the side effects I cannot go for a walk. I get these rushes and I even get these rushes when I am under an Airconditioning system and at the moment I am walking less and my doctor about my diabetics told me he told me you are not walking we need to increase your pills I mean what can I do I even tried to get a treadmill to put it right under the aircondition but the side effects are affecting me even when I am in waiting area I starting to sweat and I get all wet. In general I still have another year with these side effects and that was in May and when I finished these treatment it was 8 weeks after my blood came 0.18 I dont know how much you understand cause I don't know the meaning of this. But when I started it was 9 and before that it was only 4 and after 6 months it became 0.02 and for I don't know how it can get any lower than that I mean and that is why the</p>	<p>Physical impact – hot flushes          Physical impact– urine side effects          Physical impact – mobility issues          Changes following prostate cancer – negative - impact other medical condition          Physical side effect – sweating/hot flushes          Cancer perception – positive -PSA blood tests</p>

Appendix five– Researcher diary

<p>doctor stopped with the injections. but he still wants to see me every 6 months to monitor. In the beginning it was a bit accidental a routine check but now it is every 6 months</p>	
<p>I - So you had to make some changes?</p>	
<p>P4- Yes I cannot combine it together with this it has affected my social drinking. I mean since we are married we go out together but before that I used to go to a club where before I was a president for 10 years because of the drinking I mean even because of the drinking for the diabetics. Both of them the diabetes and cancer are against the drinking. Cause they tell me come on come for a drink as before I met her the 4 years I always went for Saturday evening and drink a bottle of whiskey and even on Sunday I used to drink half a bottle I mean I was a drinker I used to make wine and used to drink 2 bottles of wine a day but I was not an addict you know ok I used to get drunk once in a while on occasion but then I had to let it go you know and some people try to bully you youknow you like if I was afraid to die. I mean I used to know the barmen and I told him only 3 drinks and I used to make sure that I was paying the first round so that I don't feel obliged to have another round.</p>	<p>Social Impact – reduced socialising</p>
<p>P4 - three I mean when he opens the fourth and fifth I would leave them there I don't drink them. But I was going less and less because people don't like you when you live your life.</p>	



Appendix five– Researcher diary

<p>I - can you mentioned some of the physical side effects? you experienced?</p>	
<p>P4 - I mean I have the erectyleproblem and it is something that worries me sometimes because I have a younger wife. I mean sometimes she asked me take the pill and I ask her do you want to get rid of me or something what about my heart. I am not well informed I mean before not now I mean 15 years ago i did a stress test and everything was good I mean nowadays its not the same any more I mean I was a very hard worker when I arranged my house in 2007 as I was already preparing and I was saving some money for the lift I go and live on the second floor and I always go with the strairs I don't take the lift but it is not the same so I knowthat my heart is not the same and this worries me more than the cancer.</p>	<p>Sexual impact – erectile dysfunction          Psychological impact – worried about wife's needs          (Re earlier comment, give some thought to how you might organise codes into more relevant, coherent themes)          Partners' sexual needs          Sexual impact - Concerned with use of sexual aids          Provision of information – information needs          Coping - Comparing to previous self –negative          Physical impact – lack of strength / hart problem          Psychological impact –</p>

Appendix five– Researcher diary

	worried about hart
I - So you worry more about your heart than about the cancer?	
P4 - Yes that worries me more I wish there is something that I can do about it but I don't know what I can do. I mean I feel it I mean the heart of a 70 year old is not the heart of a 58 year old.	Psychological impact - Helplessness
I - So what do you feel? Do you have issues with walking?	
P4 -No I can walk what I feel is these rushes, the rushes of the side effects of the implant but when I was speaking to the doctor he told me that from 1 pill of metformin to 3 pills and it shocked me and he told me you have to for the time being half in the morning one at noon and another half in the evening and we see and start walking a bit and take more care of yourself. For example I cannot eat all fruits because I am diabetic you know I have to take care. I wish I will find somebody with the same combination as diabetics is very hard as much as cancer that is what I realised it is a cancer under a different name it is a hard disease. Although they tell you it's nothing, It is nothing? You cannot eat this you cannot eat that and even if you don't eat what they recommend and even when you take the pills you have to walk. I used to work hard in construction and I used to work in the fields I mean I made everything in my life but that is not training that is like fatigue it doesn't make your diabetic go down.	Physical impact – hot flushes  Information needs – individual with same condition (cancer diabetes)  Cancer perception – HCP vs Patient  Coping - Compare to previous active lifestyle

Appendix five– Researcher diary

	(Is this about coping or is it about loss; how things are and how things used to be?)  Physical impact – fatigue
I - Looking back at the whole treatment how would you describe your coping?	
P4 - I mean I think I coped well. I mean in the first 2 weeks I told you I had a little bit of a problem. But then the doctor told me listen forget what we told you, live your normal life because I was used to eating more vegetable but because of the gas they told me that I may have to wait or walk down the corridor or have to wait. I mean I coped well with everything I mean better if I didn't had the cancer but I coped well.	Coping - Appears to limit impact caused by cancer and treatment  (See previous comments regarding impact)
I - How would you say that your wife coped?	
P4 - She was very helpful I mean at some time there was some competition who was going to drive me to hospital and who was going to attend me to the appointments.	Support - Issue between family and partner
I - A competition between who?	
P4 - A competition between my son and my wife. She doesn't let me go alone and my son he did all my appointments on his mobile on the day before he will ask me who is going to drive you who is coming with you. My daughter is working all the day and my son works on his own and can afford more to come to	Support – from partner  Support - from family

Appendix five– Researcher diary

<p>appointments. But I don't want him to loose some of his work or time and my wife can come with me every day so it's not a problem. Even friends ask me do you want me to drive you I find help and support from my fiends and family.</p>	<p>and friends</p>
<p>I - How do you find the support from your family and friends?</p>	
<p>P4 - It is very important and not just for the cancer I mean I have been having problems all of my life from when I was 5 years old with my eyes. My mother took me to Valletta and they told her don't send him to school as he can't see I mean this is a long time ago. I did my first operation in Malta and had another accident in 1984 in the field with a tractor and had another 2 operations but I always managed and then 7 years ago I started with the diabetics and now this cancer. I mean I had aot of things in my life so this cancer did not have a big impact on.</p>	<p>Coping - Comparing cancer to previous hard periods in life (Is this about coping or impact?)</p>
<p>I - How do you think that the whole treatment impacted on your relationship?</p>	
<p>P4 - To be honest it did affected me I mean my wife is young and sometimes I don't feel although I cannot do anything sometimes I tell he to leave me alone last time she was joking she told me my vagina had an early retirement a forced early retirement. I mean what can I do haha</p>	<p>Psychological impact – worried about partner  Sexual impact - Partner sexual needs</p>

Appendix five– Researcher diary

	<p>Psychological impact – helplessness</p> <p>Coping - humour</p>
<p>I - What do you feel about this?</p>	
<p>P4 - I feel I don't tell her about it but I feel more upset about it then her. but I am saying I understand her because sometimes it will be you know that she is missing out on this but there is nothing I can do about this. I wish there is something or that I asked somebody to help me find some way if there is because I look also at my age and I am not the youngest anymore. I look you know when met we initially communicated with each other she was in the philipines and I was in Malta through a friend of her which used to work in a villa I was looking after and the agreement was that she was going to live with me. after some time she told me why don't we get married and I told her look I am older than you take care and I didn't answer her and she kept on repeating after a month or two and I told he look here I cannot marry you as there was still not divorce in Malta at that time because I got separated in 2000 and after 3 years I applied for an annulment and they started and I got my annulment in March 2006 and after this we signed and we got married but I tried to help her. Maybe you did not realise exactly what I was saying but until I was 69 I was still active I am not saying that I was active when I was younger but three times a week then when I started and last time I was speaking to Dr X .he told me that maybe after I stop with the injections maybe it will</p>	<p>Psychological impact – upset</p> <p>Sexual impact - needs of partner</p> <p>Psychological impact – helplessness</p> <p>Information needs – sexual</p> <p>Coping – attribute changes to his age</p> <p>Coping – compare to sexual active prior treatment</p>

Appendix five– Researcher diary

<p>some back. I am not losing hope completely but I don't know how it can be done I told him but don't expect anything. It's my wife I mean my problem is not my wife my problem is that I am worried about my wife something I never wished it would happen but it did. I mean I don't like the situation I am in at the moment even if I was not married again I would like to be more normal but in my case as my wife is younger than makes me a bit I mean at the back I know it is not my fault it came on me and it can be on everybody even a doctor or a professor this is not a bad thing because I killed somebody or I stole something but I still feel guilty about it.</p>	<p>Sexual impact - Hope that sexual activity can occur after finishing hormone treatment</p> <p>Psychological impact - Worried about sexual needs of wife</p> <p>Coping – normal/return to normal</p> <p>Psychological impact – guilt</p>

February 2020 - Potential themes initial interviews

**Reason for health seeking/initial symptoms theme**

Initial symptoms / health seeking

Initial symptoms / Enlarged prostate

Initial monitoring / PSA readings

Initial monitoring / Stable PSA

Symptom progression / health seeking

Other previous urological medical condition

Monitored for urological condition

Additional symptoms / health seeking

No signs or symptoms / asymptomatic

Blood test / examination

Blood test done due to other medical condition

**Treatment delay / long waiting times / private hospital**

Long waiting time for further testing

Private hospital appointment

Treatment Delay

Biopsy performed privately to avoid delays

Patient used contacts to avoid delays at hospital

No delay when seeing consultant privately

Treatment delay

## Appendix five– Researcher diary

Prostate delay caused psychological consequences

Additional treatment delay due to other illness

Treatment delay – more than 1 year

Treatment delay - cause stress

## Medical test / examination theme

Other previous urological medical condition

Monitored for urological condition

Previous medical condition

## Information needs /provision of information

Information need / second opinion from neighbor

Treatment decision not possible / provision of incorrect information?

Provision of information / treatment decision

Treatment decision not possible / provision of incorrect information?

Provision of information – treatment decision

Provision of information – incorrect details/information

Information seeking – treatment decision

Provision of information – incorrect provision of information



## Appendix five– Researcher diary

Man was angry as was not given the correct information immediately

Impact of treatment/information needs

Information needs / treatment decision

Information needs / previous patient experience

Advice from “expert” (doctor + previous patient)

Advice from previous patient

Well informed – information provision

Information seeking from previous patient

Information needs / sexual recovery

Lack in the provision of information by hcp

Concerned with use of sexual aids

Information provision issues

Information provision issues

Additional information needs

Information sources – previous patient

Lack of information provisioning

Personalised information provision

## Treatment decision theme

## Appendix five– Researcher diary

Did not wanted to go against doctor advice

Was guided/pushed to go ahead with treatment

Man was angry as was not given the correct information immediately

Provision of information – treatment decision

Guided prostate treatment

Difficult to decide on treatment option

Treatment decision – discussed with first degree relatives

Treatment decision – abroad vs local

Treatment decision – surgery not possible

Rational for treatment decision making

Proposed treatment option – Radiotherapy

Treatment decision left in hand of the patient

Information needs / treatment decision

Rational for treatment decision

Treatment regret?

## Psychological impact

Treatment delay – 1.5 year

Man was angry as was not given the correct information immediately

Treatment delay - cause stress

Emotional response – shock

Psychological impact – shocked

Psychological impact – depressed

Psychological impact – depression

Psychological impact – anger

Psychological impact – anger

Psychological impact- anger

Psychological impact – self pity

Denial / avoidance

Emotional impact of not going through surgery

Psychological impact - downcast

Time period of psychological impact

Psychological impact - worried

## Couple coping / discussion

Coping/adjusting – live with it not die with it

Coping / Support – faith/praying

Support - by partner

Support from partner

Be positive attitude – survived well

## Appendix five– Researcher diary

We - to indicate couples impact

Partner to encourage husband to use aids to control side effects

Couple willing to adjust life and lifestyle

Joint adjustment or couple adjustment

Partner to accompany husband during treatment

## Individual – impact/coping

Man to minimize impact of psychological impact of cancer

Man downplays the cancer diagnosis

Psychological impact – worried

Information seeking – online

Information seeking to deal with psychological impact

Prostate cancer normal disease

Not much impact from diagnosis– possible downplay

Impact on partner – lack of sleep

Impact on partner – worried

Impact on partner – to be patient with husband

Mood changes / psychological imp

Mood changes / psychological impact

Partner worried – asking how patient is/feel

Psychological impact – upset

## Physical Side effects

Physical side effects – increase in weight

Body image – concern

Urine side effects

Hormone treatment

Urine side effects

Impact of urine side effects on social functioning

Physical side effects – hot flushes

Physical side effects – hot flushes

Physical side effects – urine side effects

Physical side effect – mobility issues

Impact of side effects on other medical condition

Physical side effects are having negative impact on man

Physical side effect – sweating

## Compare to others / compare to pre-treatment

Compare to pre-treatment self

Comparing to others

Comparing to other worse cancers

## Appendix five– Researcher diary

Compare cancer to previous medical condition

Compare to prior treatment

Compare to others – worse

Comparing cancer to previous hard periods in life

### **Normal / return to normal**

Normal

Normal life

Normal life – kept pre-treatment life

### **Healthcare experience / perception**

Healthcare perception – radiotherapy

Positive treatment experience

Partner accompanied patient during treatment

### **Family / friends reaction impact**

Emotional reaction family/friends – shock

Family remained in close contact following diagnosis

Support from family and friends

Close relationship with family members/friends

Delayed disclosing prostate cancer diagnosis to family

Close family relationship

Family disappointed with change in treatment plan

Issue between partner and children

## **Making positive changes / changes in lifestyle**

Positive life changes – going on holiday

Changes in lifestyle

## **Perceived negative impact of changes in lifestyle**

Impact on social life

Impact on life / lifestyle changes

Impact of social functioning – reduced socialising

Social impact

Upset due to changes required for treatment

Upset about the impact of cancer treatment on life

Impact of urine side effects on social functioning

## **Sexual impact theme**

Hope to recover from sexual dysfunctioning

Not able to perform sexually

Sexual aids provided

Concerns with side effects of sexual aids

Financial cost/worries

## Appendix five– Researcher diary

Effectiveness of sexual treatment

Concern with side effects of sexual aids

Information seeking from previous patient

Information needs / sexual recovery

Time period trying sexual aids

Lack of response with use sexual aids

Treatment regret / lack of information



### **1<sup>st</sup> September 2020 - Initial codes to proposed themes**

The initial coding resulted in a total of 198 individual codes which needed to be reduced into broader themes. When reviewing the initial codes it became apparent that similar codes were assigned to different codes and these were initial combined. Examples of codes that were deemed to be similar included for example waiting time or issues with treatment delay. These codes were combined into one overarching theme which was named WAITING TIME OR TREATMENT DELAY. Several aspects were combined in this theme such as concerns of couples with treatment delay as well several strategies to avoid such delays which included for example going for a private hospital appointment.

When searching for patterns which was discovered included the psychological impact. Within this theme a broad range of psychological consequences were included and were divided into negative psychological consequences and positive psychological consequences as a result of the diagnosis and treatment for prostate cancer.

#### **Cancer Perception**

Another theme that was developed included the theme cancer perception. When describing their experiences different perception were noted. Such as the perception that prostate cancer is a 'normal' or 'common' disease for men. In addition, some of the couples had a positive perception regarding their diagnosis and perceived outcome whereas others considered their disease as a more negative or fast moving or developing disease.

#### **Coping**

Coping theme was developed which included a vast range of different styles or mechanism that couples adopted when dealing with prostate cancer. Some of the strategies adopted by the couples included for example to remain positive. Such an approach was adopted by several couples when faced with a cancer diagnosis and subsequent treatment. In addition, this often included that the diagnosis of the husband was compared to several other aspects such

## Appendix five– Researcher diary

as previous life struggles, comparing to other men who were diagnosed with ‘worse’ cancers. Compared to men who were diagnosed at an earlier age and therefore would be more negatively affected. Other aspects that were included in this theme included the ‘battle’ or ‘fight’ that these men had to face when dealing with the diagnosis and treatment.

### **Disclosing cancer diagnosis**

Disclosing the cancer diagnosis was another identified theme within the interviews and it appeared that these couples had different perspectives in their willingness to disclose the cancer diagnosis and these were combined in this theme. Whereas some of the men were open and willing to disclose their diagnosis to all their family and friends as this allowed them to get support and help others, others were not willing to disclose their diagnosis and only informed their direct family members.

### **Couple or relationship impact**

To understand the impact on the couple, a couple or relationship theme was created to organise the different codes that reflect the impact of the couple or relationship impact in one overarching theme. Within this theme several aspects such as communication or communication issues were mentioned. In addition, couples mentioned some of the changes that they adopted as a result of the diagnosis and treatment and these were further divided into negative changes and positive changes. Several of the couples highlighted the importance of the relationship and how this helped them to adjust to the situation and these were included in the marriage strength code. Another common approach adopted by these couples was to avoid speaking about cancer in order to not think about the cancer or its treatment this was often accompanied by maintaining an ‘normal’ or ‘busy’ routine.

### **Impact on men**

Several of the developed codes were related to the impact on men and I therefore combined these together in the impact on men theme. Some of these men preferred to deal with the situation on their own and would be hesitant to

## Appendix five– Researcher diary

involve other family members. These men try to gain control over the disease on their own and wanted to get the whole treatment as fast possible out of their way. Within the interview often the impact of the disease was perceived as minimal or no impact and it appeared that these men downplayed the actual impact on their life. Although the men did acknowledge that the diagnosis and disease had a range of physical consequences that impacted their body, the treatment made some men more aware of their appearance. A common strategy that was indicated included the use of humour to deal with the negative consequences.

### **Impact on partner**

The impact on partner theme included all the codes that were related to the consequences on the partner. These were further combined into negative impact and these often-included negative psychological consequences for the partner such as worrying about their husband. As some of the men preferred to deal with the situation on their own some of the partners were not involved in the whole process. However, others supported their husband by accompanying him for all treatment sessions and often keeping a record and in some cases take control of the disease and appointments. A common approach adopted by the partners was to get feedback on a regular basis to see how the men were adapting to the changes. When the men did not make any drastic changes and kept their 'normal' routine this was perceived as positive. The partners often supported their husband by searching online information and involve their husband in social activities such as going out for a coffee.

### **Pre-treatment impact**

The Pre-treatment impact theme included codes that related to the period prior their actual diagnosis. Some of the men had some signs and symptoms which made the seek for medical assistance such as urinary symptoms. However, another large portion of these men did not have any signs or symptoms and

the rise in their PSA was often detected at regular bloodtest taken for other health reasons.

### **Prostate treatment experience**

The prostate treatment experience theme included all codes that were related to their experiences. These were further divided into positive treatment experiences and negative treatment experiences. Positive treatment experiences were often related to the staff members that delivered the treatment which were perceived as helpful and often tried to accommodate specific requests such as a change in their treatment appointment time. Negative treatment experiences were codes that were related to the long preparation time for the treatment or accidents as a result of the treatment preparation.

### **Prostate cancer treatment side effects**

As the treatment for prostate cancer caused a range of side effects, these were combined in this theme. Side effects ranged from bowel and urinary side effects to hot flushes and loss of strength as a result of the treatment for prostate cancer. Another common experienced side effect was the increase in weight with some men found it difficult to cope with.

### **Sexual impact and consequences**

Although this theme could have been incorporated in the prostate cancer side effects theme, the couples recalled how the changes in sexual health had an impact on their life and relationship and therefore this was deemed to better fit in an individual theme. Although the consequences were experienced by all it appeared that some couples related the changes in sexual health due to their age whereas others felt that they were still relatively young. Although the use of sexual aids was considered and used by several couples, the potential side effects associated with their use made them concerned and often they terminated it afterwards.

### **Information**

## Appendix five– Researcher diary

The information theme included all codes that were related to the provision or seeking of information and the use of different information sources. Several of the couples re-called that they issues with the provision of information as initially were given the impression that they had a choice of treatment between radiotherapy and surgery however after a follow up meeting the surgery was no longer an option. The couples recalled how in this particular moment the provision of information was lacking and no clear reasons were provided why the treatment options was altered which caused stress and disappointment for the couple. Within this theme I also included the different sources of information which often include healthcare professionals and friends or family in addition several of the men went to speak to previous patient in order to get their opinion and experiences which they all found very helpful.

### **Support from different sources**

The couples received support during the diagnosis and treatment from a variety of sources and theses were combined in this theme. Sources included family member, other patients, HCP or colleagues and friends and religion. In addition, a few couples recalled some lack of support or unsupportive episodes and theses were also include into this theme.

### **Treatment decision**

Treatment decision theme includes all aspects that are related to the treatment decision. The different sources that were often used to make the treatment decision and reasons behind the treatment decision. Often it was perceived as the goal of the outcome the cure was more important than the side effects associated with the treatment. In addition a few couples recalled how they felt that their decision was not taken by them but guided by the HCP.

### **Treatment time or treatment delay**

Several of the couples had issues with the long waiting times which started at the diagnosis and the wait for the biopsy. An overarching theme was created

## Appendix five– Researcher diary

to include all aspects related to treatment times or treatment delay. Some couples resorted to a private clinic to avoid a delay.

### **Initial overarching themes and framework**

The initial 15 themes were further reviewed and during this process it was noted that some of these themes were related to specific stages of the prostate cancer journey. For example the concerns with delays, treatment decision and disclosing the cancer diagnosis commonly occurred prior the commencement of treatment (e.g. pre-treatment stage). In addition, other themes were more related to the treatment phase such as treatment experience and side effects. Finally it was noted that some of the approaches adopted were related to male specific and spouse specific when dealing with the consequences of prostate cancer and others were shared or more on a dyadic level. This led me to propose different post-treatment themes that were male specific, spouse specific or couples/shared. In addition, some of the initial themes also were relevant for all themes such as coping strategies, support and psychological impact and therefore these were included into the different themes. I therefore had initially proposed the following thematic framework to

I have reviewed and revised the thematic framework and in particular revised theme 3 and 4 due to similarities and overlap between these themes.

The revised thematic framework has a strong link with some of the theoretical frameworks identified in the literature (the behaviour of one member of the couple impacts the other/couple). This has been identified as relationship enhancing behaviour/relationship compromising behaviour or positive dyadic coping/negative dyadic coping.

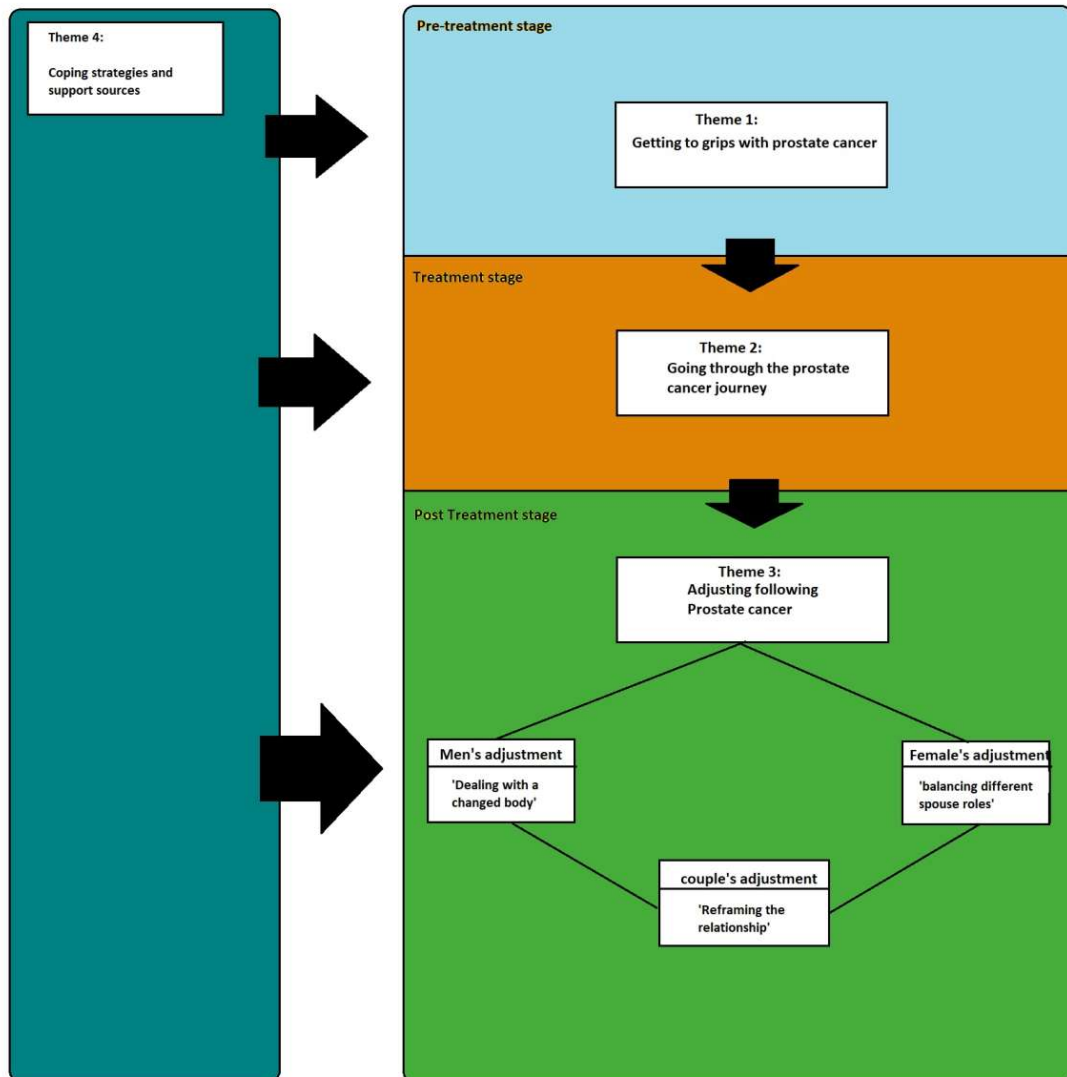
Relationship enhancing behaviour/positive coping includes a range of different behaviour and aspects such as self-disclosure to partner, supporting the other partner, relationship engagement, delegated dyadic coping (partner takes on roles to reduce burden) and common dyadic coping (couples engage in emotional- or problem focused coping together). Relationship compromising behaviour/ negative coping includes aspects that negatively impact the adjustment such as avoidance, criticism, and pressure withdraw (pressuring partner to talk about cancer, leading to withdrawal).

## Appendix five– Researcher diary

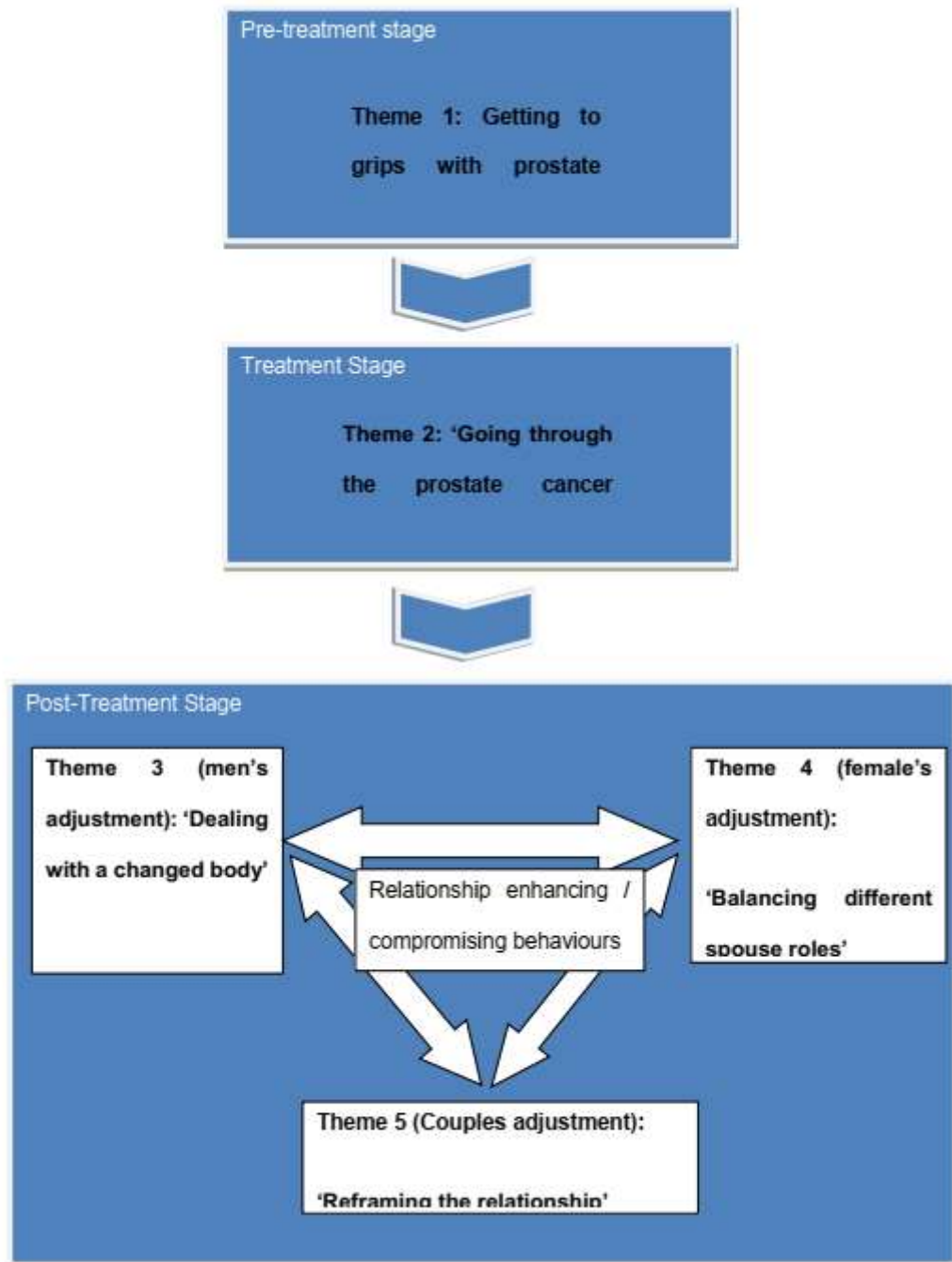
As both relationships enhancing and compromising behaviour has been identified in this study, the revised thematic framework provides a better and clearer understanding of how couples cope and adjust following prostate cancer treatment.



## Initial thematic framework



## Revised thematic framework



## Final thematic framework

