



A study on the Partnership Programme of  
a Public Umbilical Cord Blood Bank in the  
Kingdom of Saudi Arabia: A Critical Realist  
Approach

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“بِسْمِ اللَّهِ الرَّحْمَنِ الرَّحِيمِ”

In the name of Allah

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# Dedication

This thesis is dedicated to my father, Omar Yousef Al-Somali, who died of cancer while I was pursuing my PhD. My father was a man of education, and thus, he was a constant source of inspiration and support throughout my life, particularly in my professional endeavours. My chauffeur, idol, mentor, and my guardian angel of my dreams were all in one person: him. God bless him with a place among the highest dwellers in paradise! May his gentle soul rest in peace. Ameen.

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# List of Abbreviations

**AABB:** the Association for the Advancement of Blood and Biotherapies

**BM:** Bone marrow

**CBB:** Cord Blood Banking

**CD34:** Classification Determinant 34

**CME:** Continuing medical education hours

**CR:** Critical Realism

**FACT:** Foundation for the Accreditation of Cellular Therapy

**GTT:** Glucose Tolerance Test

**HSCs:** Haematopoietic stem cells

**HCPs:** healthcare professionals

**KSA:** Kingdom of Saudi Arabia

**ILR:** Integrative Review

**IRB:** Institutional Review Board

**MUD:** Matched Unrelated Donor

**MOH:** Ministry of Health

**NIT:** New-Institutional Theory

**PHMD:** Public Maternity Hospital Department

**PIS:** Participant Information Sheet

**TDF:** Theoretical Domains Framework

**TNC:** Total Nucleated Cell count

**UCB:** Umbilical Cord Blood

**UCBB:** Umbilical Cord Blood Banking

**UCBD:** Umbilical Cord Blood Donation

**UCBBH:** Umbilical Cord Blood Bank Hospital

# Glossary of Terms

**Agency:** is the individual's ability to behave autonomously and make his/her own decisions.

**Allogeneic transplant:** is a treatment modality in which a patient receives healthy stem cells from a matched related or unrelated donor to replace their own ill bone marrow. This occurs after the patient has received intensive doses of chemotherapy and or radiation.

**Causal Mechanism:** a collection of interacting structures involved in producing an observable phenomenon.

**Causal Power:** refers to the ability of a mechanism to have empirical consequences.

**Causal structure:** the central structure to a mechanism that acts as a driving force giving empirical consequences.

**CD34:** Classification Determinant 34 (CD34): is a protein molecule found on the surface cell and serves as an adhesion factor between cells. Clinically, it is a critical indication for determining the quality of stem cells, particularly those intended for transplantation.

**Continuing medical education (CME):** It is a credit-based system in which healthcare professionals earn CME hours for participating in educational programmes.

**Cryopreserved:** a technique used to cool and store the bodily tissues or cells at very low temperatures to keep them viable for future usage.

**Demi-regularity:** Demi-regularities: are trend or patterns that reveals, to some extent, individual's reasoning under certain conditions. 'Events or regularities occur imperfectly over space and time'.

**Engraftment:** is the process by which the transplanted stem cells begin to grow and produce healthy cells.

**Epistemic fallacy:** It is the reduction of ontology to epistemology, or the reduction of being's or the world's nature to our knowledge of it. Bhaskar (1975) coined the term epistemic fallacy to describe the overt focus on intricate details in the social world.

**Ex-utero UCB collection:** collect cord blood after the baby and placenta have both been delivered.

**GvHD:** Graft Versus Host Diseases is a life-threatening immunological reaction that occurs when the recipient's body rejects to accept the donor's stem cells.

**Human leukocyte antigens typing (HLA typing):** is a laboratory test used to determine the degree of compatibility between donors and recipients in the case of a stem cell transplant (the perfect HLA typing equals 6/6).

**In-utero UCB collection:** collect cord blood after the birth of the baby and prior to placental delivery.

**Structures:** are recurring and stable patterns of arrangement that either enhance or constrain the empirical events. Given that the whole is greater than the sum of its part', structures are entities with an independent existence, power and properties that are clearly distinct from those possessed by their parts. For example, structures cannot be reduced to things like behaviours, variables, or practices. They exert distinct causal effects, whether or not individual realise them, depending on the contextual conditions of the event.

## Abstract

**Background:** Umbilical cord blood (UCB) is a rich source of stem cells for a wide range of malignant and non-malignant diseases. Many countries have a public banking system where donors' UCB can be stored and used within the public health system.

**Aim:** This study aimed to identify the reasons for a decline in the UCB collection rate at a public UCBB programme in the Kingdom of Saudi Arabia. The barriers inhibiting the UCB collection programme, and the facilitators aiding it were investigated. The UCB programme relied on midwives' voluntary and parent participation and this study focused on these relationships and their impact.

**Methodology:** A critical realism (CR) study was conducted to understand the cause of the decline in UCB collection and donation rates. Thirty-seven semi-structured interviews were conducted with UCB nurses, policymakers, midwives, antenatal nurses, obstetricians and mothers. Field notes and documentary review were also used as part of data collection. Data were analysed using critical realist analysis.

**Results:** Three barriers were distilled from the critical realist analysis. Firstly, the lack of clear leadership and supervision led to confusion regarding different policies, logistical problems, and a lack of motivation to participate. Secondly, the current UCB nurses lacked the necessary soft skills and broader nursing experience to establish a strong working relationship with the primary hospital maternity department's midwives in order to handle the parents' needs. Finally, the parents' lack of understanding about the programme, combined with their educational background, allowed superstitions and other cultural practices to discourage them from donating. This was worsened by poorly timed consent-seeking procedures. UCB nurses were also poorly trained in the UCB programme. These barriers interacted closely with each other and resulted in the systemic failure of the UCB programme whilst the altruistic nature of UCB donation aligned well with Islamic values and served as a facilitator.

**Conclusion and recommendations:** A decline in the rate of UCB collection and donation is a result of the complex interplay of the three barriers mentioned above within the UCB programme. The roles of the midwives and UCB nurses should be reconsidered, appropriate training and incentives need to be in place, and these must be cemented within the policy documentation.

# Chapter 1. Introduction and background

## 1.1. Introduction

Umbilical cord blood (UCB) collection is an important component for the treatment of malignant and non-malignant diseases (Ali and Al-Mulla 2012). Haematopoietic stem cells can be cultivated from umbilical cord blood donated (UCBD) from mothers during childbirth (Herlihy and Delpapa 2013). There are more than 160 national UCB banks worldwide providing UCB stem cells to patients suffering from diseases for which Haematopoietic Stem Cells (HSCs) transplant is a viable treatment option (Kurtzberg 2017). When compared with bone marrow (BM) sourced stem cells UCB offers many benefits, these include availability, reduced risk of infectious disease transmission and reduced risk of graft-versus-host disease. Many nations have opted to collect and store UCB units nationally rather than rely on external UCBB. In 2006, the Kingdom of Saudi Arabia (KSA) established the country's first public UCBB. The context of this thesis is at the umbilical cord blood collection (UCBC) sites for the public bank in KSA. This chapter introduces the study which is presented in four sections. The first section describes the research question, the aim and objectives of the study, the rationale behind the choice of topic, and the rationale of the study. The second and third section provides the background and context of umbilical cord blood banking (UCBB) and gives an overview of the KSA, which is the setting for the current study. The last section outlines the structure and organisation of the thesis.

## 1.2. The Study Synopsis

### 1.2.1. Research question

The central research question of the study presented in this thesis is:

What are the causes of the declining UCBC and UCBD rates at a public UCB bank in KSA?

### 1.2.2. Thesis statement

This thesis investigated the causal roots of the declining rate of a UCBC programme in KSA. Using Critical Realism (CR) analysis, areas of underperformance and facilitating elements were identified. The study revealed that the causes of the falling rate were organisational lapses, recruitment practices and a reduction in training and education services. The

facilitating element, which aided the programme, is the potential benefit it promises for both healthcare professionals (HCPs) and future recipients of donated UCB for treatment.

### 1.2.3. Study aim

This research aims to theorise an explanation for the potential barriers and facilitators, which contributed to the decline in UCBD and collection rates in KSA. This can inform recommendations to maintain the UCB infrastructure and to stabilise the UCBC rate to meet market demands. Figure 1 depicts the collected UCB units spanning from 2006 till 2018. The graph shows that during the initial years of the programme, the collected UCB units rose, however from 2012 the general trend was that collected UCB units declined rapidly. This thesis aims to understand why the collected UCB unit rate declined during these years. The general trend was that the collected UCB was increasing due to the beginning of the programme, the UCB collectors collected all units with little discernment in criteria. However, in 2011, the collection criteria were tightened to conform with FACT standards, and that coincided with a decrease in the number of UCB units collected. For example, the new UCBC guidelines exclude UCB donations from mothers who have specific health conditions, like as hypertension, diabetes, twin pregnancies, or a meconium-stained cord. The UCBD and UCBC rate then continued to decline from 2014 to the present, prompting this study to search for the causes for this fall in donation and collection rates. This research began in 2019.

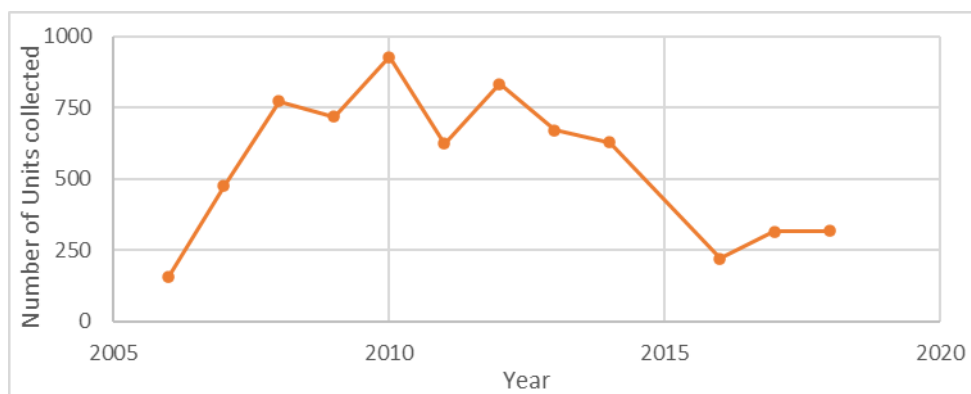


Figure 1. Number of collected units per year shows the rise and fall of unit collection (UCBBH, 2019).

### 1.2.4. Study implications

The aim of this study is to uncover the strengths and weaknesses of a public serving UCBB in KSA. The results provide a solid foundation for further experimental studies in the same context. As there was a decline in UCB units collected in the local area, further interventional and experimental studies can test variables that may impact on UCBC rates. Prior to



interventional studies it is advisable to understand the phenomena as it exists, thus assessing barriers and facilitators provides an in-depth view of the UCB programme. Lastly, studies on UCBB procedures in KSA are limited, this study can fill gaps in the research regarding the sociocultural elements that impact decisions to collect and donate UCB.

### 1.2.5. Study Rationale

My interest in UCBB grew when I started my nursing career as a paediatric haematology and oncology nurse. As in some cases, the last or only therapeutic option for children was to undergo a long journey of stem cell transplantation. Unfortunately, despite the average size of families in KSA being large, approximately 40% of Saudis may not have a matched relative donor. This necessitates the establishment of alternative stem cell sources in KSA such as UCB (Ayas et al. 2010). Due to the importance of UCB in stem cell transplantation in KSA, the decline in UCBC and UCBD is particularly concerning. Study of background literature regarding UCBC and UCBD practices revealed that there were gaps in research regarding the perceptions of policymakers. As a result, issues and barriers relevant to policy decisions were largely unknown, it was therefore considered important to gain the perspectives of policymakers, mothers and HCPs to unearth the reality of the phenomena.

CR meta-theoretical approaches had not been applied to UCB research in this manner previously. In this research, various perspectives were analysed in accordance with the open system of CR, as opposed to an isolated study in a controlled environment. Previous research in this field also used quantitative approaches, often through surveys, to ascertain why mothers did or did not donate UCB or to understand HCPs collection practice. Qualitative studies providing rich experiences were scant, furthermore many studies investigated the individual factors influencing UCBC rates. I aimed to contribute to the evidence base of UCBD and UCBC in the context of KSA. Lastly, research concerning UCBC and donation in KSA has been limited. This new context required qualitative approaches to distinguish the situation in KSA from that of other settings that have been previously researched.

### 1.2.6. Study Setting and Design

This study was set in KSA and conducted at two sites: the tertiary hospital that established the UCBB (UCBBH) and a Public Hospital Maternity Department (PHMD) where the UCB is collected from donors. The UCBBH houses the UCBB and hires the UCB nurses who are deployed and based in the PHMD. The antenatal and midwifery departments based the PHMD, along with the UCB nurses were responsible for the collection of UCB.

CR was used in this research to understand the causes behind the decline in the UCBC and UCBD. Within CR, there is an understanding that there are complex elements at play beneath the phenomenon of interest. Using CR, this research seeks to better understand these complex elements within the UCB programme in KSA, why there is a decline in UCBC rates, what are the barriers for UCBC and UCBD and how they can be overcome.

This study utilised qualitative methods to fulfil the study aim and answer the research objectives. Mothers, obstetricians, antenatal nurses, midwives, UCB nurses and policymakers were recruited for semi-structured interviews. In addition, the researcher observed the above participants in the field. Observation notes on the partnership between the UCB teams and the antenatal departments were recorded. Lastly, documents relating to the UCB programme were reviewed. Documentation and observations provided further background and veracity of the participant's perceptions during interviews. The interviews, document analysis and field observation data led to a multi-method CR study that explored the issues within the UCB programme in KSA.

Data was analysed using the steps of CR analysis. Raw interview data was transcribed and translated from Arabic to English. The data was then coded and abstracted before the CR process of abduction and retroduction, which eventually resulted in the distillation of the causes of the decline in UCBC and UCBD, as well as the barriers and facilitators of the UCB programme. These steps are fully explained in the methods chapter (Chapter 3).

## 1.3. Background of UCBB

This section examines the benefits of UCB stem cells, history of UCB banks both globally and regionally (in KSA), as well as the ethical concerns surrounding UCBB collection and processing procedures, debate surrounding UCB units and current UCB market demands.

### 1.3.1. Benefits of UCB Stem Cells

The UCBC procedure is a non-invasive, painless, and quick process compared with collection of stem cells from other sources (i.e., bone marrow or peripheral blood apheresis). Once the UCB unit is harvested, screened, and stored, it is instantly accessible (within days) if a transplant is needed, no further preparation is required (Bart 2010; Welte et al. 2010). UCB transplant also exhibits a lower incidence of viral transmission and graft-versus-host disease, even when there is a partial mismatch between the donor and recipient's Human Leukocyte Antigens Typing (HLA typing) (Stanevsky et al. 2009; Gluckman et al. 2011; Webb 2013). Due to the immaturity of UCB stem cells, there is a greater likelihood of HLA match, this makes

them a feasible choice for more patients (Bart 2010). Even with a match difference of 4/6 or 3/6 HLA typing, UCB stem cell transplantation results were superior or comparable to those achieved with a perfect match (6/6 HLA typing) (Gluckman et al. 2011; Mayani 2011; Atsuta et al. 2012; Terakura et al. 2016). Thus, UCB banks have sprung up worldwide to meet the requirements of recipients, both locally and internationally.

### 1.3.2. UCBB history and role

Gluckman et al. (1989) launched the first clinical trial utilising UCB derived stem cells in 1989, this triggered a series of UCBC and storage efforts for future uses. In 1991, the first UCBB was established in New York City (Ballen et al. 2015). Public UCB banks are now available in many developed and developing countries. By 2017, more than 160 global public UCB banks were operating across 36 countries with a total inventory of 800,000 saved UCB units (Kurtzberg 2017).

Unlike private UCB banks, public UCB banks serve the whole society, not only those with the financial means to pay for unit storage. Public UCB banks are responsible for collecting and processing donated units for recipients who need a matched UCB unit from a related or unrelated donor, at no additional cost to the donor (Yoder 2014; Guilcher et al. 2015). Once the UCB unit is donated to a public UCBB, the storage service is no longer exclusive to the donor's family, who waived their ownership of the UCB unit for the benefit of public banks (Skabla et al. 2010). This is then recorded within both national and international banking databases for allocation to a suitably matched recipient for therapeutic use (Maheshwari et al. 2013; Yoder 2014). The key factor here is that there is no contact between donor and recipient if a unit is used for transplantation purposes (Ballen et al. 2015).

On the other hand, private banks provide the same service, but the UCB is specifically stored for the use of the donors and their families, should a future stem cell transplant be necessary (Mayani 2011; Yoder 2014). Preservation costs for a UCB unit tend to vary depending on the country and banking centre. Globally there are 225 commercial UCBB facilities spread across 52 countries (O'Connor et al. 2012; Parents Guide to UCB Foundation, 2021). In 2017, Kurtzberg reported that there were more than 5 million privately stored UCB units.

### 1.3.3. UCBB in KSA

The KSA has two public UCB banks, these are located in the capital city of Riyadh. In 2003, the government authorised the establishment of the country's first UCBB at a tertiary specialist hospital. As of 2016, this hospital conducted approximately 364 UCB

transplantations (Shaheen et al. 2020). In the past five years, the studied UCBB has provided 90% of the UCB units used in transplantations in KSA. The inventory size of this bank has approximately 5400 archived UCB units (Shaheen et al. 2020). The studied UCBB had a partnership programme with several collection sites within Riyadh city to build up the bank inventory as in Table 1 (Al-Haidar 2013). However, at the time of this research, there were only two active partnerships with the UCBB: the PHMD and the UCBBH itself.

Table 1. The collection sites in collaboration with the studied public UCBB.

Place	Collection centers
Riyadh City	King Faisal Specialist Hospital and Research Center (KFSH&RC)
	Al Yamama Hospital (AYH)
	Security Forces Hospital (SFH)
	King Khalid University Hospital (KKUH)
	King Saud Medical City (KSMC)

In 2011, King Abdullah International Medical Research Centre (KAIMRC) launched the country's second public UCBB (KAIMRC 2015). The bank stored 2000 UCB units, all of which were obtained locally from the hospital's maternity department (Matsumoto et al. 2015). Both public UCB banks provide family storage services for those with a known medical history of illnesses for which UCB transplantation is a suggested alternative i.e., a pre-emptive banking service (Jawdat et al. 2018). If parents indicate a desire for private UCBB, several commercial UCB banks offer prophylactic banking services as a type of biological insurance. In this context, it is important to emphasise that the UCB units collected by these private firms are shipped to foreign storage facilities such as Cells4life in the UK (Jawdat et al. 2018). Families in KSA wishing to donate their infant's UCB must give birth in one of the national UCB banks' partner hospitals for the blood to be harvested, processed, and preserved.

#### 1.3.4. UCBB legislation in KSA

UCB units are biological products derived from human sources and the KSA bases its judicial system on the Sharia (Islamic law). There is a strong entrenchment of Islam in this society and culture. Further, in KSA, healthcare is public, and it is a cost-free service; healthcare is a fundamental privilege for all citizens, including the use of the UCBB and recipient stem cell transplantation. When a new medical procedure is released to the public, people are hesitant

to participate unless an Islamic cleric approves it within the parameters of Islamic ruling (Fatwa). Thus, UCBB practices and policies are based on a Fatwa declared in 2003 by the Muslim World League's Islamic Jurisprudential Council (Fadel 2007). Public UCB banks are controlled and licensed by the Ministry of Health (MOH) and the Saudi Food and Drug Authority for medical or research purposes (AABB 2015). The MOH established a national committee in charge of regulating UCBB and formulating licensing processes (Saudi's MOH 2007). In 2011, the MOH suspended some offices in the KSA suspected of unlicensed collaboration with overseas commercial banks (MOH 2009). The international banking standards for UCBB were first developed in 1997 by the Net-cord and the Foundation for the Accreditation of Cellular Therapy (FACT<sup>1</sup>). It now encompasses regulations and criteria for UCB harvesting techniques, processing, and storage. It also regulates ex-vivo experiments to expand UCB unit's volume for future applications (Gluckman et al. 2011; Ballen et al. 2015). Since 2012 and 2015, the two public UCB banks in KSA have been FACT accredited (KAIMRC 2015; Matsumoto et al. 2015).

While UCB is stored in KSA for public use, UCB units are also sometimes exported to overseas transplant centres for use if the required UCB unit is available. The export of UCB units help to support public banks financially, in addition to the reliance on government funding (Matsumoto et al. 2015). Similarly, in situations where there is no matching UCB unit in the KSA UCBBs, UCB units are also imported from overseas at a cost of around 40,000 USD per unit.

### 1.3.5. Ethical issues surrounding UCBB

Both public and commercial UCBB are fraught with ethical quandaries. Some of the difficulties in public banking include the units' ownership, and donor recruitment procedure. Another ethical debate on public UCBB is the anonymity and confidentiality of donor information when reporting any infectious or genetic abnormalities discovered in UCB samples (Petrini 2013; Stewart et al. 2013).

The HCP's participation in commercial UCBB also raises some ethical questions (Fox et al. 2008). For instance, are HCPs obliged to fulfil expectant parents' desire to save their UCB units for future private usage? Are prenatal care providers ethically obligated to the newborn? Are the prenatal staff ethically accountable to educate expecting parents on a regular

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<sup>1</sup> FACT accreditation: It is the gold standard for cellular therapies excellence, such as stem cell transplant. It certifies that the accredited organisation has managed to meet the standards in all aspects of stem-cells therapies.

basis about private UCBB services? If private UCB banks pay obstetricians or midwives to collect UCB units, this could be considered an ethical issue, where the antenatal team promoted private UCBB because of monetary incentives.

For parents to make a well-informed decision, HCPs are ethically responsible for disclosing the following in the UCB educational package: Information on UCBB options, the capabilities, benefits, and limitations of UCB stem cells should be clearly stated by HCPs; especially for families with a known medical history of diseases curable by stem cell transplantation (Fox et al. 2008; Roh et al. 2014). This was supported by Herlihy and Delpapa (2013) who stated that the decision on whether to store UCB units privately or to donate them to national banks was an individual choice for parents. Hence, HCPs should not presume that a mother has accurate UCBB information. Instead, it is their duty to offer unbiased information about the various UCBB alternatives so that parents can make an informed decision. The consent process, UCBC procedure, and the required screening test must all be addressed in education sessions. HCPs should inform parents about the UCB collecting procedure and ensure them that donor information will be kept confidential (Vijayalakshmi 2013; Jordens et al. 2014; Karagiorgou et al. 2014).

### 1.3.6. Quality of UCB units

Quality of UCB units is influenced by the method of collection, the health of the mother, the health of the newborn, the processing methods, the storage conditions, and genetic factors (Munro et al. 2019). Currently, there are specific criteria for eligible donor mothers and neonates. For example, mothers with conditions such as gestational diabetes, hypertension, and mothers of advanced age (> 35 years) should not donate UCB. Furthermore, it is not permitted to collect UCB from neonates who are under 3.5 kilograms, neonates who are premature or have a meconium-stained cord. (Nunes and Zandavalli, 2015).

To preserve the quality of UCB units, sterile collection methods and appropriate storage are essential (Meyer et al. 2006). Moreover, larger volumes of UCB taken from full-term babies typically have stronger engraftment<sup>2</sup> potential and include more stem cells (Brunstein et al. 2017). Infections or illnesses affecting the mother can lower the quantity of stem cells and compromise the quality of the UCB unit (Meyer et al. 2006). Processing methods like freezing and thawing may have an impact on the survival of cells and the quality of the unit (Brunstein

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<sup>2</sup> Engraftment is the process by which the transplanted stem cells begin to grow and produce healthy cells.

et al. 2017). Proper storage conditions, including temperature and humidity control, are crucial to maintaining the quality of UCB units over time (Meyer et al. 2006).

Genetic factors, such as HLA matching, can affect the potential for successful transplantation (Barker et al. 2015). The quality of UCB obtained from public UCB banks in the United States of America (USA) was the subject of a study by Armstrong et al. (2018). The quality of the UCB units was evaluated using several criteria, such as cell count, viability, and bacterial contamination. The data came from nine public UCB banks, most UCB units in the USA were found to be of good quality overall, satisfying the minimum standards for cell count and viability. The study did note several issues with UCB quality maintenance, including bacterial contamination, low cell count, and low viability. Conversely, in India, quantitative studies analysed the quality of collected UCB and found that the quality was not as high as that of the USA (Patyal et al. 2018). Patyal et al. (2018) cited the need to bolster the quality of collected UCB units as the UCBB was still in its infancy in India.

In the Middle East, studies quantitatively examined the quality of UCB (Reuther et al. 2022; Mousavi et al. 2019). Reuther et al. (2022) examined the quality of UCB in the public bank in KSA and found bacterial contamination to be minimal with high viability and high stem cell count. This makes the UCBB comparable to its Western counterparts in quality, despite the quantity of units being below the target inventory size. In these studies, quality refers to the viability of UCB units and their efficacy in treating patients in need of stem cell transplantation. However, there is a debate amongst stakeholders in relation to the quality of UCB units.

### 1.3.7. The debate surrounding UCB units

What is considered a higher quality UCB unit and potential unintended consequences of UCB collection have been the subject of much debate. Midwives and obstetricians are duty-bound to prioritise the health of mothers and neonates, this affects the rate of UCB units collected. Machin (2016) discussed the balancing act that is needed in the UK regarding UCBC., Machin (2016) found that midwives were concerned about the timing of cord clamping, and the position of clamping, during a time of heightened risk for mothers directly after birth. However, from the phlebotomists' perspective, clamping the cord later and positioning the clamp away from the neonate could lead to UCB units being unusable. Due to the reduced collection volume. The participants in Machin's (2016) study questioned the rationale behind the timing of cord clamping and its effect on the mother, the newborn, and patients with blood disorders. The volume of blood taken, which was used as a gauge of UCB quality, was

similarly impacted by the timing of cord clamping. Participants indicated that limiting the amount of UCB obtained may produce a high-quality sample without changing the time at which the cord was clamped. This balance between the health of the mother and neonate and the collection of usable stem cells for recipients is crucial for the benefit of all stakeholders. Machin's (2016) article highlighted the precarious balance for all stakeholders with regard to UCBC. In addition, the midwives, obstetricians, and UCB bankers were interested in both preserving the health of expectant mothers and babies and aiding in the gathering of high-quality UCB.

Mercer et al. (2014) and Rabe et al. (2023), on the other hand, supported the infusion of UCB into the neonate, they considered it important for a newborn to receive an adequate amount of blood from the placenta at birth. It must be stated however, that it is essential to observe the health of the neonate and mother before undertaking UCB collection. Mercer et al. (2014) and Rabe et al. (2023) stated that placental transfusion, where the baby receives blood from the placenta, played a significant role in the baby's transition to life outside the womb, it avoids hypovolemia and boosts organ perfusion. In the event when early cord clamping is needed, guidance provided by the Resuscitation Council UK (2021) recommends performing the milking technique, to quickly transfer blood from the umbilical cord to the baby, prior to undertaking neonatal resuscitation. The World Health Organisation recommends allowing at least one minute for UCB to transfuse into the neonate before the cord is clamped (NHS Lanarkshire 2021; Rabe et al. 2023).

### 1.3.8. UCB extraction, processing, and storage

UCB extraction is a painless and simple procedure that occurs following birth (Grieco et al. 2018). This procedure should be performed by a skilled professional, certified in UCBC techniques, in collaboration with the team in the delivery room. The collection can take place either in-utero<sup>3</sup> or ex-utero<sup>4</sup> after a vaginal or caesarean section delivery. The in-utero collection uses the frequent contractions of the uterus to enable blood flow from the placenta and cord vein (Skabla et al. 2010). Some earlier and current research revealed no substantial difference between the techniques. Following birth, the cord is clamped and sterilised at the venepuncture site to reduce the possibility of contamination. The collection needle is then inserted into the umbilical cord venule. This, with gravity assistance, allows the blood to flow freely into a sterile sealed system bag, for blood collection. The

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<sup>3</sup> In-utero: Collect UCB after the birth of the baby and prior to placental delivery.

<sup>4</sup> Ex-utero: Collect UCB after the baby and placenta have both been delivered.



practitioners must place the bag at a lower level than the placenta (Skabla et al. 2010). The volume of the UCB unit is a key criterion for determining the quality of the unit (Reuther et al. 2022). The greater the volume of UCB units, the higher the unit quality. For a recipient, quality of UCB usually refers to a set of qualities and standards that make the blood suitable for use in medical procedures or scientific investigations (see the previous section, the quality of UCB units). Depending on the intended application and the procedures followed by medical practitioners and researchers, there are a number of different variables that may apply (Mousavi, et al. 2019). An umbilical cord generally discharges between 50 and 150 ml of blood (Armson 2005). Other parameters, such as Total Nucleated Cell Count (TNC) and Classification Determinant 34 (CD34) counts, must be considered when evaluating the quality of UCB units. Interestingly, some studies revealed a positive correlation between unit volume and TNC (Jan et al. 2008; Keersmaekers et al. 2014; Sward et al. 2019). These criteria (TNC and CD34) differ per unit, according to the practitioner's skills and/or maternal and new-born factors (Philip et al. 2015; Tanacan et al. 2018; Munro et al. 2019; Nguyen et al. 2020). For example, cord clamping time, cord length, baby birth weight, and the mother's condition are all factors that may influence the quality and volume of UCB units.

High-quality units may be collected when the cord length exceeds 30 centimetres and the new-born's weight exceeds 3500 gm (Armson 2005; Ciubotariu et al. 2018). The time of UCB clamping is a major issue in the UCBB field. However, when cord clamping occurs within 30-60 seconds of delivery, the possibilities of harvesting a good quality unit increase (Armson 2005; Ciubotariu et al. 2018). Delayed cord clamping is linked with a substantial reduction in the mean UCB volume and TNC ( $p < 0.0001$ ), especially when the clamping time exceeds two minutes after delivery (Ciubotariu et al. 2018). The same source reported that clamping the cord immediately or within 60 seconds after delivery had no significant effect on TNC or blood volume. Thus, many UCB banks now consider that the delay to cord clamping should not exceed 60 seconds (Armson 2005; Ciubotariu et al. 2018).

Hence, it is essential to consider these criteria while collecting UCB units. As UCB banks must comply with international laws governing UCBD to qualify as a licensed UCB banks, the majority of public UCB banks store only units equal to or greater than 70 millilitres (Frändberg et al. 2016). In contrast, commercial UCB banks store units regardless of TNC or blood volume. This is because private banks are not scrutinised as closely as public UCB banks (Ballen et al. 2015; Shearer et al. 2017). In Ballen et al.'s (2015) systematic literature review, they stated that private banks were under less governmental regulation as private banks work on a for-profit model. It is also essential to note that there are some ongoing studies to

expand cell volume through ex-vivo trials, which may enhance the quality of UCB units (Pineault and Abu-Khader 2015; Hosseini et al. 2017). Following collection, the UCB units must be processed within 48-72 hours to preserve cell viability (Rubinstein 2009; Martin et al. 2011). Undisturbed stem cells frozen at -196 °C have a greater chance of retaining their biological viability for up to 20 years (Broxmeyer et al. 2011).

### 1.3.9. Global Market Demand

The UCB banks have lately been confronted with significant challenges such as high operating expenses and the decline in donor recruitment. Generally, in the stem cell transplant field, finding a well-matched related donor is the ultimate treatment option for many diseases. Yet, the recipient may not always have such an opportunity. Finding a compatible UCB unit was essential for treating these patients with stem cell transplants. Over recent years, however, there has been a noticeable reduction in UCB market demand owing to the availability of haploidentical alternatives, which showed faster engraftment compared to UCB for the treatment of several disorders (Magalon et al. 2015; Kapinos et al. 2017). A haploidentical transplant occurs when the donor and recipient are related but their tissue types are only half-matched. Haploidentical stem cell transplantation has gained popularity as an alternative to UCB transplantation for some diseases (Wagner et al. 2021).

According to Wagner et al. (2021) the average survival outcomes of haploidentical transplant are comparable to those of UCB. This raises the question of whether it is necessary to grow and maintain these banks considering the shift in UCB market needs. Although haploidentical transplant is on the rise while UCB transplant is on the decline, recent advances in UCB transplant, such as UCB expansion to improve engraftment, make UCB transplant a viable option again (Nagler and Mohty 2022). The trend toward UCB is likely to continue to expand with the aim of improving the global quality of healthcare (Roura et al. 2015).

Current published work in this field revealed that UCB was one of the most active areas in human regenerative medicine, it offers significant clinical, social, and economic benefits (Strong et al. 2018; Haw et al. 2019). For example, a recent meta-analysis and systematic review study showed that both UCB and haploidentical transplantation were considered equally effective options for adult and paediatric patients with hematopoietic malignancies (Li et al. 2020). Particularly, for those without matched related donors, UCB transplantation can be considered as an alternative.

Due to the rapid evolution of the stem cell transplant field, the needs of the UCB user community are constantly changing i.e., the UCB banks operate on a shifting landscape. This

shift in UCB market demand places an additional burden on the UCB bankers who want their stored units or data to remain relevant to public need (Williams 2018). Thus, the concept of the first generation of UCB banks, which focused on quantity rather than the quality of units, has been reviewed. This heralded the beginning of the "second-generation" of UCBB (Williams 2018). This phase emphasised the importance of cellular dosage for a good quality UCB unit. For example, a quality unit must contain a certain cellularity number of TNC to be saved. Thus, various ex vivo trials on stem cells are ongoing for cellular expansion purposes with promising findings of novel approaches to increase cellular dosage and accelerate stem cell recovery (Mayani 2011). Despite the widespread success and challenges that UCB banks encounter, the future demand of the UCB market remains unpredictable. It is now worth considering the UCBC as an infrastructure rather than just a banking system. The need for infrastructures may grow as access to UCB units becomes costly should the UCB programme fail. Despite the fluctuations in UCB demand, some UCB units are necessary for the stability of transplants and treatments for those in need. As the UCBB system is underdeveloped, it is at continued risk of closure. Those most affected by this instability would be those people who are unable to afford UCB units from international sources. Concerns about the quality of stored UCB units were beyond the study scale. Instead, the research sought to identify potential obstacles and facilitators to the collection of UCB units and the recruitment of donors for a successful UCBB infrastructure.

## 1.4. Background of Study Setting

This section below is about the KSA where the current study was conducted. It provides an overview of the country's location, socio-cultural and religion context of KSA. The purpose of the overview is to understand the study's context and what the consequences might be for UCBD and banking.

### 1.4.1. Overview of KSA

Manufacturing and trade generated in KSA in 2016 was approximately 2.5 million Saudi Riyals (equivalent to 666,700 USD), with a total national income of 55,769 USD per capita. (General Authority for Statistics KSA 2017). The KSA was first established in 1932, it is geographically unique as it links two major continents, Asia and Africa, and is found in the south-western corner of Asia. The KSA is the Arab world's second-biggest country covering around two million km<sup>2</sup> and has a population of 35,013,414 (Saudi's MOH 2020). The oil boom in the KSA in 1934 boosted economic growth, this propelled it to the top of the list of richest countries

with regards to individual income (Mills 1986; Simpson 2002). In a short space of time almost all KSA's population transitioned from living as travelling Bedouins to dwelling in a permanent urbanised environment.

#### 1.4.2. Healthcare system in KSA

Healthcare services are free of charge for all Saudi citizens in KSA through the MOH primary and secondary (hospitals) healthcare facilities. Furthermore, there are several partly or completely independent hospitals, such as private healthcare facilities, teaching, tertiary, and military hospitals. The geographical locations of primary healthcare centres are fairly widespread and serve the whole population including those living in remote, rural areas. They manage routine medical issues including seasonal flu symptoms. When specialist medical treatment is needed, such as stem cell transplant, the patient is directed to one of the MOH facilities or to tertiary hospitals for free specialised medical treatment (Albejaidi 2010).

Lengthy waiting lists is a major issue in non-emergency services. As a result, many Saudis are compelled to seek alternatives, most of which are specialized (tertiary) hospitals. These tertiary healthcare facilities are typically fee-based, or they exclusively serve particular groups of patients such as National Guard troops and their relatives. They may also expand their services for serious conditions, such as oncology and organ transplantation cases. Cardiac illnesses, oncology cases, pulmonary diseases, and diabetes mellitus are the most common healthcare problems in KSA (WHO 2012). More than 90,000 people in KSA die from non-communicable diseases, making up more than 78% of all deaths in 2012 (WHO 2014). As shown in Figure 2, CVDs cause 45.7% of all deaths, cancers account for 10.3%, pulmonary illness for 3.3% and diabetes for 4.6 % (WHO 2014). The likelihood of dying prematurely (i.e., before the age of 70 years) from one of these non-communicable diseases is 17% (WHO 2014).

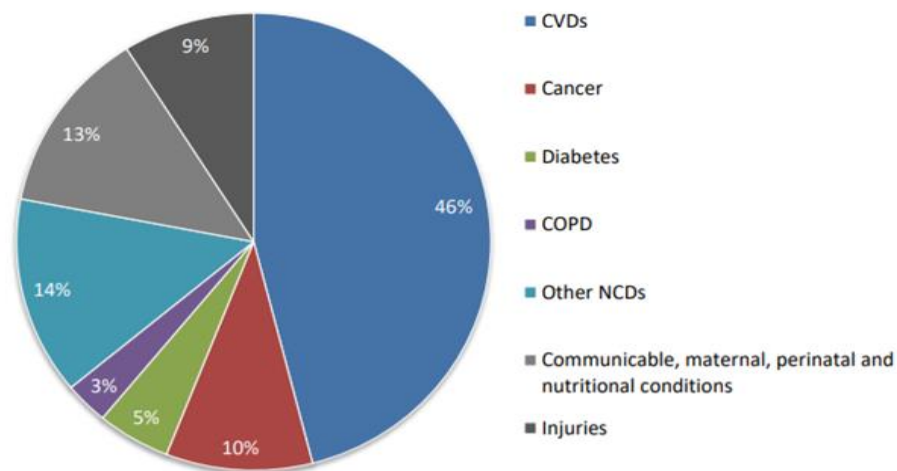


Figure 2. Proportional Mortality (Percentage of Total Deaths, All Ages and Both Sexes) (WHO 2014).

Although the KSA was developed relatively recently, several forefront institutions of healthcare research have arisen such as King Khalid Specialist Hospital (KKSH), KFSH&RC, and KAIMRC as in Figure 3 below. All three centres are situated in Riyadh and compete fiercely for research funding, formal accreditation, facilities, staff, national initiatives, and public projects. In the capital alone, there are two vying hepatic transplant centres, two public UCB banks, and two independent BM donor databases with each asserting supremacy over the other. For Saudi patients, more than 90% of HSCs transplants are conducted in the KSA, in the five main tertiary facilities, while the remainder are conducted overseas (Ministry of National Guard and Health Affairs 2020; Shaheen et al. 2020). In 1984, KSA became the Arab world's pioneer in the stem cell transplantation field, conducting approximately 500 allogeneic<sup>5</sup> transplants annually, later, KSA began to harvest UCB units for the cultivation of HSCs in 2003 (Shaheen et al. 2020).

<sup>5</sup> Allogeneic transplant is a treatment modality in which a patient receives healthy stem cells from a matched related or unrelated donor to replace their own ill bone marrow. This occurs after the patient has received intensive doses of chemotherapy and or radiation.

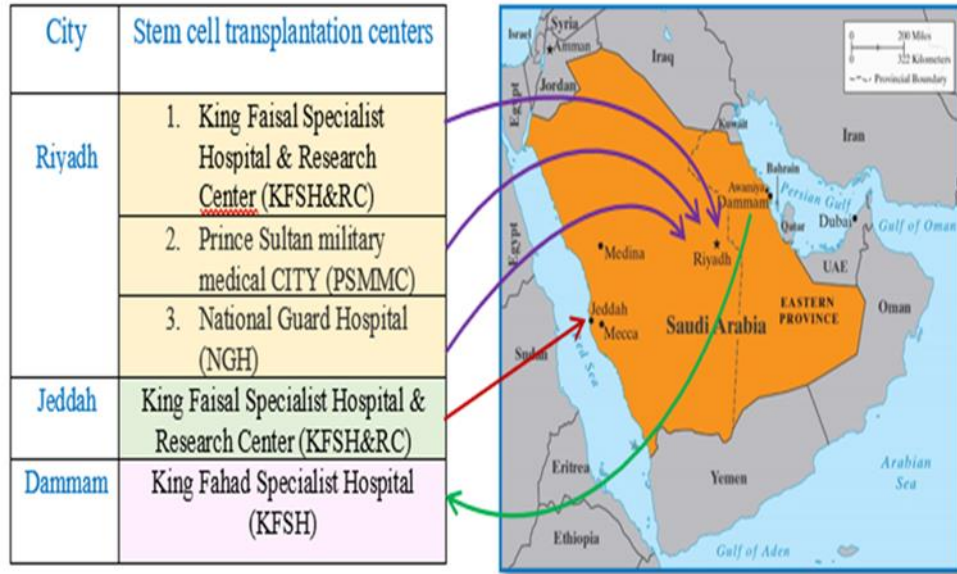


Figure 3. Centres for Stem Cell Transplantation in KSA (Shaheen et al. 2020).

### 1.4.3. The religious and socio-cultural context in the KSA

Many elements influence KSA culture, these include religious stands, customs, environmental influences, and the education and economic level of individuals. Ethical principles in KSA are shaped by a mixture of Islamic ideologies and social customs derived from KSA societal tribal foundations and passed on through tribal generations (Aldossary et al. 2008). These factors prioritise the community functioning through upholding respect and trust over and above personal liberty or autonomy. For example, the education system is separated by gender and females are not permitted to socialise with males who are not family members. Men are expected to be the protectors of women and to be breadwinners for the family, whereas women are expected to take care of their home and children (Altorki 1986). These societal norms and rules have influenced women's roles and autonomy, prohibiting them from participating in activities such as living independently even though Islamic teaching does not include such prohibitions.

Indeed, entering the labour market and pursuing a career in nursing was one of the first professions that women were encouraged to pursue (Bryant 2003). Women in KSA find it challenging to make decisions and decide what is best for them due to societal norms (Aljaouhari 2013). In some families, women are not allowed to make a decision on whether to undergo a caesarean section without the approval of their partner. Similarly, obtaining informed permission for UCBD is a choice in which the spouse must be included. In this study, including fathers' perspectives about UCBD were not possible due to the set-up of the PHMD. Fathers do not enter the PHMD wards except under specific circumstances such as providing

consent for treatments, or for consultation upon complications in labour (see methodology chapter, recruitment and sampling section for further explanation).

The two main global Islamic jurisprudence bodies have their headquarters in the KSA, their rules and injunctions affect Muslims globally; for instance, the kingdom's stance on all types of blood donation affects all Muslim countries. Giving or donating blood was deemed as *halaal* (permissible) after Islamic clerics recognised the similarity between extracting blood from one's body for medical benefit as similar to the Islamic prophetic tradition of *hijamah* (cupping) where blood is drawn from the body by using vacuum cups (Jordens et al. 2012).

Marriage between cousins is encouraged in KSA tribal society not as a random habit, but as a matter of honour that is actively encouraged. People are graded inside these civilizations based on their lineage, history, and legends toward guests and allies, the purity of their blood, and their financial position (i.e., cattle ownership and control over water sources). According to the tribe's social hierarchy, a person's social standing is affiliated by the lineage of his parents (Adlan 2014). Starting with his paternal ancestry, his social status among his tribe is decided by parental bloodline. Someone's rating will be lowered if his mother is not part of a similar or greater tribe. Most tribal marriages occur amongst first cousins as marriage between powerful tribes is costly and is often utilised as an instrument for political concord among tribe leaders. Individuals who defy that informal agreement jeopardise their offspring's social standing within the tribe. Consanguineous marriage seems to have been a relatively common occurrence in KSA throughout history. In 1997, the incidence of consanguineous marriages in KSA was 51.3%, which is much higher than the incidence in many other nations. Although this figure decreased to 39.8% in 2018, the frequency of consanguinity marriage remained high amongst educated individuals (Al Husain and al Bunyan 1997; Mahboub et al. 2020). This was particularly true amongst first cousins, due to familial background and personal desires rather than individual age or academic level.

Four out of every ten paediatric patients who were diagnosed with cancer fulfilled the criteria for hereditary cancer susceptibility syndromes (HCSS), most of which were triggered by consanguinity marriage (Jastaniah et al. 2018). Furthermore, KSA's incidence rate of  $\beta$ -thalassemia and Sickle Cell Disease is listed as one of the highest in the Middle East (0.05% and 4.50%, respectively) (Alsaeed et al. 2018). Despite their large families and greater genetic similarity, nearly 40% of Saudis were unable to find suitable relative donors after screening for relative HLA typing and markers such as infectious disease, and malignant disorders (DeZern and Gondek 2020; Alsuhaibani et al. 2015). This has heightened the importance of

arranging for alternative options across the KSA (Ayas et al. 2009). The purpose of this thesis is not to debate whether consanguinity is a suitable way to identify a relative match donor or UCB unit, or for the extent to which it contributes to the significantly greater incidence of genetic disorders among Saudis. However, it is essential to note that UCBB is especially useful in societies where intermarriage between cousins is common. The more consanguineous marriages that occur, the more likely their children will have shared disease genes. This puts them at a higher risk for congenital abnormalities, mental disabilities, leukaemia, any hereditary illnesses, and particularly those inherited disorders that are widespread in that ethnic community. Sickle cell anaemia and thalassemia are two well-known hereditary disorders that are more common in particular ethnic groups.

## 1.5. Thesis Structure

This thesis is divided into ten chapters. This first chapter provides a brief overview of the thesis rationale, aim, questions, and study design. In addition, the contextual background of the case, laying the foundation for a clear understanding of the phenomena at hand, is briefly introduced. Chapter two highlights the literature review and possible barriers and facilitators of UCBC in studies with various contexts. Chapter three includes the methodology, it introduces CR meta-theory, the assumptions associated with, and the theoretical core of the paradigm. This chapter also explores other likely philosophical structures and the implications of their use. It outlines the study method and recruitment practice. Chapter four describes the main themes of participant responses, which are then re-analysed and abstracted through abduction-retroduction process as in Chapter five. Chapter five outlines the proposed mechanisms accounting for the empirical events retold by participants in Chapter four. Chapter six then covers the study discussion and recommendations, the barriers and facilitators of UCBD and collection are stated and compared with the literature. Lastly, the thesis ends with Chapter seven, which involves the study conclusion, implications, and the possibility of future studies.

## 1.6. Conclusion

This now concludes the first chapter of this thesis. The background setting of the study has been thoroughly explained and an outline of the study rationale, objectives, impact and brief data collection and data analysis methods have been described. Chapter two includes the literature review and search methods and strategies.



## Chapter 2. Literature Review

### 2.1. Introduction

The literature review aimed to collect and describe findings in the research field regarding elements that can influence UCBD and UCBC for public banking. Additionally, the findings of the review provided a base understanding of factors concerning UCBC for data collection and analysis. Evaluation of the methods and measurement tools to discern possible UCBC barriers and facilitators occurred throughout the review. During literature analysis, the methods utilised, sample size and recruitment processes, results and possible areas of bias were assessed. Lastly, the chapter conclusion included a synopsis of findings, a simple model derived from research and implications for future research and practice. Gaps found in this review were identified in an attempt to satisfy unanswered questions raised by the literature review.

This literature review adhered to the integrative literature review (ILR) model, which encourages methodical search strategies, critiquing literature, and a coherent display of findings along themes found in the research. Published studies that considered possible UCBC facilitators and barriers were at times challenging to gather. This was due to the nature of individual publications themselves, many of the studies found did not aim to extract barriers and facilitators and therefore it was necessary to be deliberate concerning keywords.

### 2.2. The Search Strategy

#### 2.2.1. Review questions

This review explores the literature on UCBD and UCBC to identify obstacles, which may have hampered the growth of the UCBBs inventory size. Additionally, it looked at existing facilitators or interventions for enhancing the donor recruiting process as well as healthcare professionals' motivation and involvement in this programme. To fulfil the review purposes, it was necessary to include all parties contributing to UCBD and UCBB such as donor mothers, healthcare professionals, policymakers and bank management. Thus, more specific queries were generated from the research question with an attempt to answer them through this review:

- What is the healthcare professionals' predisposition to educate pregnant mothers about the importance of UCBB? What is their predisposition level to collect UCB units?
- To what extent are parents willing to donate or preserve their babies' UCB?
- What are the barriers and facilitators to increase the rate of the stored UCB units from parents' perspective?
- What are the barriers and facilitators to increase the rate of the stored UCB units from healthcare professional perspective?
- What are the obstacles and specific facilitators most frequently reported as highly important by public UCB banks?
- What tools have been used to measure these barriers? Are they reliable, valid and suitable to answer the research question?
- What kind of interventions have been suggested to improve the public UCBB rate?

### 2.2.2. Integrative literature Review

An ILR is a distinctive approach that analyses, critiques, and synthesises available evidence on a topic of interest. Such an approach can generate novel frameworks or a comprehensive understanding of the studied phenomenon (Torraco 2005). The ILR model provided the format for this literature review. ILRs are commonly performed to address either a well-explored (or mature) or a newly emerging topic. There is a lack or omission of UCB banking literature in KSA, particularly the social implications of parental UCBD and the problems practitioners confront in this field.

Although the methodology chapter thoroughly explains the philosophy of CR, it is important to demonstrate that CR is consistent with the ILR. CR combines realist ontology with relativist's epistemology. In terms of ontology (what is the nature of existing things), CR acknowledges the presence of a mind-independent, fileable, and structured reality. Whereas CR epistemologically (what can humans know and how they may know it) argues that knowledge is valid only relatively to a particular context, society, or individuals. In accordance with CR, ILR incorporates the rigour of the positivist approach while acknowledging the subjectivity of the relativist's paradigm, where meaning interpretation is regarded as a valid source of evidence (Callahan 2010). This is particularly relevant when analysing emergent or controversial concepts. Cooper (1998) outlines the literature review process as follows: problem conceptualisation, literature search, data evaluation, analysis of findings, and finally, result presentation. Ensuring scientific credibility when conducting an integrated literature

review requires close attention to the potential risks to validity (Russell 2005). A few measures were taken in each phase of the literature review process to mitigate validity concerns.

To validate stage one (to identify the research problem), the researcher should develop conceptual and operational explanations of study variables (Torraco 2005). These definitions should not be overly specific since this may influence the quality of findings. Also, overly wide study variable definitions may conceal important research specifics and a misunderstanding of results (Russell 2005). For instance, in this review, I searched for barriers that pertain to parents and HCPs for UCB donation and collection. The search resulted in extensive operational and conceptual definitions. However, thinking of the review objective, some barriers were not necessarily barriers for this research context. Therefore, it was essential to prioritise barriers that could be incorporated into KSA in this pioneering scheme. Rather than starting with a limited search, I had to first list the obstacles and then filter them down. For example, private CBB was not possible in KSA as currently the practice is solely for public banking, therefore research concerning UCBB policies regarding private banking were excluded.

### 2.2.3. Search Method

To validate the literature search, a well-defined systematic search strategy was implemented using the specific keywords listed in table 2.

Table 2. Key words for the study systematic literature search

Umbilical cord blood	Collection	Barriers and facilitators	Healthcare professionals	Parents
Placenta* blood	Bank*	Knowledge, Awareness	Nurse, antenatal nurses	Mothers/woman/parents
Cord blood	Stor*	Attitude	Midwife/midwives	Pregnant Mother/woman
Stem cell*	Preserv*	Competen*, train*, educat*	Healthcare personnel/healthcare provider*	Expect* Parent
	Donat*	Practice/practise, Behavi*	Physician/Obstetricians/ doctor	Couple
	Collect*	Perception, View, opinion/Belie*		
		Policy/Policies Regulation*/guideline		

The search derived electronic sources from: The British Nursing Index, CINAHL, Web of Science, MEDLINE PubMed, Scopus, and The National Cord Blood Scientific Publication. Screenshots of some of the databases utilised in the study's literature review are provided in appendix A.

Additionally, a series of manual searches were conducted to identify whether there were other relevant sources, which may not have been included within the electronic search. Manual searches included reviewing relevant articles' bibliographies and tracking citations. Key information in each study was summarised in a table (i.e., author, year of publication, participant groups etc.). Given the number of reviewed studies, this summary table identified obstacles and potential facilitators to UCB donation and collection.

To validate the process of data evaluation and analysis the reviewer role is to ensure that all assumptions and their inferences are clarified (Cooper 1998; Russell 2005). Thus, I needed to be clear about what point I am taking from each study. For example, some of the papers aimed to measure the level of knowledge, however, I specifically took into consideration demographic findings and discussed them further to identify the barriers. I was looking beyond the aims of included studies, I tried to focus on relevant findings that answered the review questions in each paper. Furthermore, it was critical to differentiate evidence derived from primary and secondary data sources (Cooper 1998; Russell 2005). So, only primary sources were included in this review. Secondary data sources (i.e., literature review studies) could contain the researchers' bias and conflicting interests, it was essential to remain neutral and not to depend on the researchers' assumptions and interpretations. A reasonable attempt was made to write a thorough report of ILR that could easily be followed (Russell 2005).

The review included two systematic literature searches. The initial search focused on studies of the barriers and facilitators to recruit UCB donors and to harvest the UCB units regarding healthcare practitioners. The second search focused on studies that examined the obstacles and facilitators of UCB donation among parents. Published materials from 1991, when the first UCBB was established in New York, to 2021, was considered to follow up on any modifications or changes which occurred, and that could enhance the UCBB inventory size.

#### 2.2.4. Inclusion and exclusion criteria

Table 3 below summarises the criteria used to identify the papers included in this literature review.

Table 3. The study's inclusion and exclusion criteria

Inclusion Criteria	Exclusion Criteria
Population: expecting mothers and HCPs who provide antenatal and labour care services.	Studies reporting on the recipients of UCB units for stem cells transplantation
Primary research studies that examined possible barriers and facilitators to parents' and HCPs willingness to donate or collect UCB units.	Secondary research studies (e.g., review studies)
Studies published in the Arabic and English languages	
All research designs (quantitative, qualitative, mixed methodological)	

### 2.2.5. Data Appraisal

The studies assessed in this review were inspected and critiqued. This was done to evaluate the quality accordance with various study designs, to ascertain three main areas.

- The validity of study findings
- The study's findings
- The usefulness of findings

The CASP checklist provides systematic guidelines, which enable the researcher to critically appraise the aforementioned areas of publications. The weaknesses and strengths of research studies are highlighted thus enabling the researcher to decide on the publications' usefulness with regards to findings (Munn et al., 2014). The suitability of study design and its application to local generalisations is also addressed using the checklist. Guided by the CASP checklists, notable methodological elements were summarised in a data extraction table, along with other features of the studies reviewed. This provided an insight into the methodological rigour and quality of the reviewed studies, which guided the writing of this chapter. However, as this is essentially a narrative review, the narrative provided by the articles was of greater priority than methodological rigour and no studies were excluded as a result of the critical appraisal process.

The findings from the literature search were synthesised and presented in categories of themes to allow for a narrative to be constructed (Torraco, 2005). The results of the search were outlined in Tables 4 and 5 (Chapter 2) and the commentary on quality can be found throughout the narrative.

### 2.3. The Review Results and Outcomes:

The initial search resulted in 441 papers, 56 papers being duplicates. After removal of the duplicates, the abstracts of the remaining 385 papers were reviewed to filter those that best addressed the review objectives. A total of 192 studies were excluded because they were deemed irrelevant to the primary review question, leaving 193 articles for further assessment. However, only 112 full articles were retrieved, 81 articles were not accessible via the university library privileges. The 112 papers were then examined to determine whether they satisfied both the inclusion and quality criteria. This stage yielded 75 articles in total, 25 studies examined the obstacles facing the HCP when collecting the UCB (Table 4), 44 papers assessed the challenges parents faced when donating the UCB (Table 5). Only 6 articles addressed the concerns of both healthcare practitioners and parents about UCBD and UCBC (see the below PRISMA diagram, Figure 4).

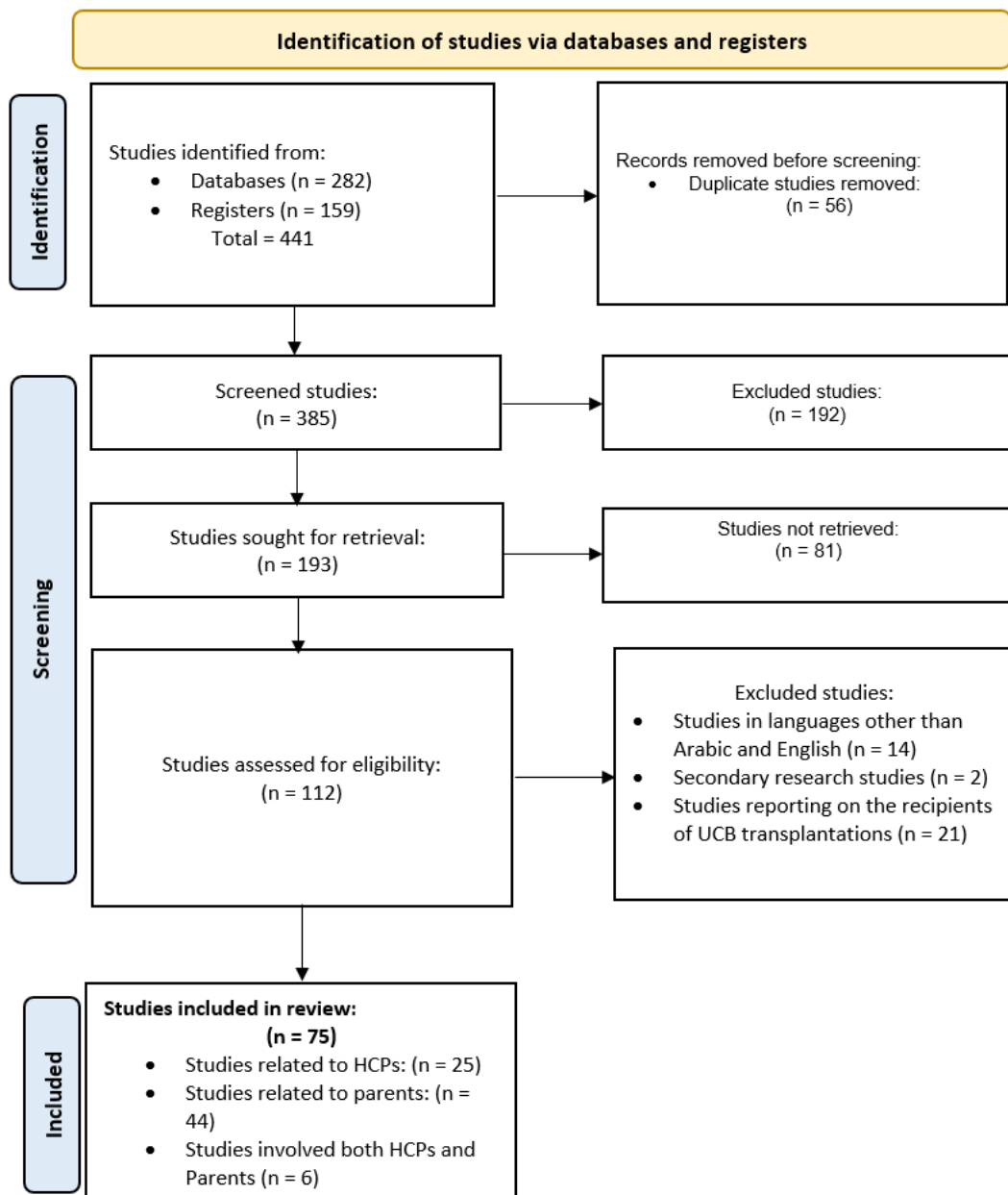


Figure 4. PRISMA chart for the literature reviewed to identify the barriers and facilitators of UCBD and UCBC for HCP and parents.

Table 4. Search results for HCP barriers and facilitator according to study design and settings.

Search results from 1991-2022	Studies including HCPs (Total N=25)	Study's Country	Studies included both parents and HCPs. (Total N=6)	Study's Country
<p><b>Total of 25 articles on Obstacles and facilitators to UCBD and UCBC among HCPs</b></p>	<p><u>Quantitative (n=14)</u>                      Peberdy et al. (2020a); Abdulrazeq et al. (2020); Badawy et al. (2020); Gupta et al. (2019); Lee et al. (2019); Armstrong et al. (2018); Gholap et al. (2018); Patyal et al. (2018); Das et al. (2017); Moustafa and Youness (2015); Jawdat et al. (2014); Hatzistilli et al. (2014); Roh et al. (2014); Walker et al. (2012).  <u>Quantitative Interventional (n=5)</u>                      Duffy et al. (2009); Mohammed and El Sayed (2015); Abdel Fadeel et al. (2018); Sward et al. (2019); Mansour et al. (2020).  <u>Qualitative (n=5)</u>                      Peberdy et al. (2020b); Haw et al. (2020); Haw et al. (2019); Machin (2016); Machin et al. (2012).  <u>Mixed methods (n=1)</u>                      Tada et al. (2011).</p>	<p><u>North America (n=5)</u>                      Haw et al. (2020); Sward et al. (2019); Haw et al. (2019); Armstrong et al. (2018); Walker et al. (2012).  <u>The UK (n=3):</u>                      Machin (2016); Machin et al. (2012); Duffy et al. (2009).  <u>Europe (n=1):</u>                      Hatzistilli et al. (2014).  <u>Australia (n=2):</u>                      Peberdy et al. (2020a); Peberdy et al. (2020b).  <u>Middle East (n=7)</u>                      Abdulrazeq et al. (2020); Badawy et al. (2020); Mansour et al. (2020); Abdel Fadeel et al. (2018); Mohammed and El Sayed (2015); Moustafa and Youness (2015); Jawdat et al. (2014).  <u>Asia (n=7):</u>                      Lee et al. (2019); Gupta et al. (2019); Patyal et al. (2018); Gholap et al. (2018); Das et al. (2017); Roh et al. (2014); Tada et al. (2011).</p>	<p><u>Quantitative (n=5)</u>                      Mistry et al. (2018); Bhandari et al. (2017); Tuteja et al. (2016); Matijević, et al. (2016); Ginori et al. (2015).  <u>Mixed methods (n=1):</u>                      Salvaterra et al. (2010).</p>	<p><u>North America (n=1)</u>                      Bhandari et al. (2017).  <u>Europe (n=3)</u>                      Croatia and Italy:                      Matijević, et al. (2016); Ginori et al. (2015); Salvaterra et al. (2010).  <u>Asia (n=2)</u>                      India:                      Mistry et al. (2018); Tuteja et al. (2016).</p>



Table 5. Search results for parents' barriers and facilitator according to study design and settings.

Search results from 1991-2022	Studies including parents only (Total N=44)	Study's Country
<p><b>Total of: 44 articles on Barriers and facilitators to UCBD and UCBC among parents</b></p>	<p><u>Quantitative (n=31)</u>            Zomer et al. (2021); Szubertet al. (2020); Panasiti et al. (2020); Catherine et al. (2020); John-Olabode et al. (2020); Grano et al. (2020); Saleh, (2019); Jawdat et al. (2018); Rajendran et al. (2018); Ciubotariu et al. (2018); Azadpour et al. (2018); Tufekci et al. (2017); Matsumoto et al. (2016); Kim et al. (2015); Alexander et al. (2014); Karagiorgou et al. (2014); Bioinformant (2014); Parco et al. (2013); Vijayalakshmi (2013); Screnci et al. (2012); Jordens et al. (2012); Suen et al. (2011); Katz et al. (2011); Shin et al. (2011); Manegold et al. (2011); Palten and Dudenhausen (2010); Hassall et al. (2008); Fox et al. (2007); Grossman et al. (2005); Danzer et al. (2003); Fernandez et al. (2003).</p> <p><u>Quantitative Interventional (n=6)</u>            Rashed and Shehata (2018); Ibrahim et al. (2018); Grieco et al. (2018); El-Sayed et al. (2018); Philip and Seeta-Devi (2017); Jordens et al. (2014).</p> <p><u>Qualitative (n=5)</u>            Porter et al. (2012); Rucinski et al. (2010); Dinc and Sahin (2009); Sugarman et al. (2002); Sugarman et al. (1998).</p> <p><u>Qualitative interventional (n=1)</u>            Padmavathi (2013)</p> <p><u>Mixed methods (n=1)</u>            Meissner-Roloff and Pepper (2013)</p>	<p><b>South and North America (n=8)</b>  <u>Brazil, Caribbean, Mexico, USA, Canada:</u>            Zomer et al. (2021); Ciubotariu et al. (2018); Fox et al. (2007); Perlow (2006); Rucinski et al. (2010); Grossman et al. (2005); Fernandez et al. (2003).            Sugarman et al. (2002); Sugarman et al. (1998).</p> <p><b>Australia (n=3)</b>            Jordens et al. (2014); Porter et al. (2012; Jordens et al. (2012).</p> <p><b>Europe (n=11)</b>  <u>Poland, Italy, Switzerland, Germany, France, Spain, UK, Croatia, Greece</u>            Szubert et al. (2020); Panasiti et al. (2020); Grano et al. (2020); Grieco et al. (2018); Karagiorgou et al. (2014); Parco et al. (2013); Screnci et al. (2012); Katz et al. (2011); Manegold et al. (2011); Palten and Dudenhausen (2010); Danzer et al. (2003).</p> <p><b>Middle east (n=7)</b>  <u>Lebanon, UAE, Saudi, Jordon, Egypt, Iran</u>            Saleh (2019); Jawdat et al. (2018); Rashed and Shehata (2018); Azadpour et al. (2018); Ibrahim et al. (2018); El-Sayed et al. (2018); Matsumoto et al. (2016).</p> <p><b>Africa (n=3)</b>  <u>South Africa and Nigeria</u>            John-Olabode et al. (2020); Alexander et al. (2014); Meissner-Roloff and Pepper (2013); Hassall et al. (2008).</p> <p><b>Asia (n=11)</b>  <u>Turkey, India, Korea, Hong Kong:</u>            Catherine et al. (2020); Sahoo and Rana (2020); Rajendran et al. (2018); Tufekci et al. (2017); Philip and Seeta-Devi (2017); Kim et al. (2015); Vijayalakshmi (2013); Padmavathi (2013). Suen et al. (2011); Shin et al. (2011); Dinc and Sahin (2009).</p> <p><b>One International Studies (n=1)</b>  <u>USA, Canada, Caribbean, Mexico, Europe, Asia, Middle East, Africa, Australia and New Zealand.</u>            Bioinformant (2014)</p>

The 75 articles were read and briefly summarised to define the core elements, themes, and main findings. The themes were developed according to the frequency in which they appeared within the reviewed studies. For example, many papers recorded information on participants' UCB knowledge, which resulted in it becoming a theme.

As in Table 4 above, there were 25 published articles describing the barriers and facilitators that HCP (including managers) encounter when recruiting donors or collecting the UCB units. Out of 25 studies, around 76% of the studies were quantitative, with 14 studies using a survey design and five studies utilising interventional measures to improve the UCBB efficiency. The remaining 24% were qualitative studies (n=5) and a mixed methodology study (n=1). More details of the study settings, nature and key findings are in Tables 4 and 5 above. The findings of this literature review are grouped into the categories shown in Table 6.

Table 6. Literature review themes.

<b>Review Themes</b>	<b>Contents</b>
Knowledge, awareness, and attitudes towards UCBB and UCBD. Knowledge and compounding factors: <ul style="list-style-type: none"> <li>• Education level</li> <li>• Income</li> <li>• Location</li> </ul>	<ul style="list-style-type: none"> <li>• HCPs knowledge of UCB</li> <li>• Parents' awareness of programme existence</li> <li>• Other organisational information (e.g., UCB unit storage and technical requirements).</li> <li>• Parents and HCPs' attitude towards UCBD and UCBB</li> <li>• Parents' knowledge and preferences for public or private UCBB</li> <li>• Benefits and risks of UCBD and UCBC</li> </ul>
Sociocultural factors impacting UCBD and UCBC	<ul style="list-style-type: none"> <li>• Family construct and societal rules</li> <li>• Religious and contextual factors that impacted UCBB decisions</li> </ul>
Bureaucratic and organisational barriers <ul style="list-style-type: none"> <li>• National level</li> <li>• Organisational level</li> </ul>	<ul style="list-style-type: none"> <li>• National health priorities</li> <li>• Workload for HCPs and collection hours</li> <li>• Bureaucratic factors that impacted UCBC</li> </ul>
UCBD facilitators	<ul style="list-style-type: none"> <li>• Additional facilitator that could not be categorised into the aforementioned themes</li> <li>• Individual and large-scale factors that had power to influence UCBC and UCBD</li> </ul>

### 2.3.1. Knowledge, Awareness and Attitudes to UCBD and UCBB

Many studies (n=24) concentrated on the level of parental knowledge or awareness of either UCB, UCBB<sup>6</sup> or UCBD. Forty-six percent of these studies found that participants had low knowledge of UCB, while only 8.3% (n=2) of the studies described parents as having a satisfactory knowledge of UCB uses. Similarly, 60% of studies reported that parents only had a low level of UCBB knowledge. Some studies focused on parents' awareness of UCBD (n=5) with three of those citing low knowledge of donation. Most of the studies that investigated parents' awareness found they had little knowledge of UCB, UCBB or UCBD.

However, the way in which knowledge and awareness was measured varied and was difficult to consolidate. This was due to the variety of methods used for deducing parental knowledge as well as the subject matter. Some studies utilised qualitative, semi-structured interviews to gauge parents' awareness of UCB, others tested their sample on in-depth UCBB processes as well as forms of UCBD. For example, in India, Padmavathi (2013) recorded the effects of regular UCBB teaching on parents' ability to recall UCBB information, the sample was tested using interviews. Initially, more than half their sample exhibited low knowledge of UCBB, the sample was then provided with training sessions and talks with obstetricians. The sample was tested again and 70% were able to demonstrate that they had adequate information on UCBB. In this study, Padmavathi did not detail the data collection method, or the scale of measurement used to determine the satisfactory levels of UCB knowledge.

Some articles were descriptive studies investigating general knowledge of UCB (Jawdat et al. 2018; Rajendran et al. 2018; Szubert et al. 2020), while other studies were more detailed and explanatory, looking at the factors affecting UCB knowledge levels such as education levels, age and geography (Meissner-Roloff and Pepper 2013; Karagiorgou et al. 2014; John-Olabode et al. 2021).

The literature search revealed the following results, 10 studies explored healthcare professionals' awareness of UCBB, the processes of collection and provision of interventions through collected UCB. Peberdy et al. (2020a) assessed the knowledge, attitudes, and practices of HCPs regarding third stage labour, UCB practices and donation and found that only 35% were aware of the uses for collected UCB. Gupta et al. (2019) found that 84% of participants were unaware of the international guidelines for UCBC. Similarly, in Jordan

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<sup>6</sup> UCB incorporates both private and public banking options. This literature review aims to focus on public banking and is thus the default definition. Private storage is specified when it necessary to refer to private banking or storage.

nearly 75% of obstetricians reported the absence of hospitals guidelines or infectious disease screening for UCB units (Abdulrazeq et al. 2020). The lack of knowledge and awareness amongst the midwives and nurses regarding UCBB was consistent across nine of the 10 articles (12.3% of all search results) investigating awareness and knowledge of HCP, except for a study with midwife participants in China (Lee et al. 2019). This exception indicated that midwives had scored relatively highly when surveyed on the medical uses of UCB (mean = 77%), particularly those who held a masters level qualification ( $p < 0.05$ ). Lee et al. (2019) findings could indicate that educational attainment levels of HCPs can influence UCB knowledge. Interestingly, Lee et al. (2019) was the only study which found that midwives had a high level of knowledge on UCB.

Duffy et al. (2009) found many midwives understood the uses for UCB as a treatment modality for haematological illnesses. Sixty-six percent of the sample ( $n=39$ ) knew there were other uses for UCB stem cells in regenerative medicine and that they could be used to treat further conditions such as immunology and genetic disorders. Following the training on the UCB programme, 74.6% ( $n=44$ ) of midwives found it had addressed their concerns and upskilled them on the sterility system and techniques for UCBC.

In Roh et al. (2014), in Korea, researchers investigated obstetricians' knowledge of several aspects of UCBB including the collection procedure, legal regulations, limitations and potency of UCB banks. The obstetricians' knowledge of UCBB was found to be below the researchers' expectations, although the acceptable knowledge level was not clearly identified by the researchers. Two other studies conducted in India discovered that obstetricians were familiar with the UCBB domain but were miseducated about the potency of UCB stem cells (Tuteja et al. 2016; Mistry et al. 2018). According to Tuteja et al. (2016), 26% of obstetricians claimed that UCB could heal all genetic diseases in children. Similarly, Mistry et al. (2018) noted that 30% of obstetricians claimed that UCB units were a valid therapy source for autism and all genetic conditions.

A more recent study in the USA observed that the vast majority (79%) of clinicians (advanced nurse practitioners, paediatricians etc.) did not discuss the UCBB options with expecting parents (Armstrong et al. 2018). Comparatively within the same study, general paediatricians with 10 years or more experience were significantly more likely to communicate the UCB topic with expected donors ( $P < 0.001$ ) than their younger colleagues. Approximately 52.8% ( $n=250$ ) of Armstrong et al.'s (2018) participants cited the lack of UCBB knowledge as the main reason for not discussing the storage option with the expecting parents. Roh et al.

(2014) similarly revealed that even though the majority of obstetricians (82.7%) in Korea successfully identified the clinical use of UCB units, their confidence in discussing storage options with expectant parents was low.

In the studies concerning knowledge and awareness for both HCPs and parents, the type of knowledge and awareness of both differed from article to article. Some studies focused on UCB subject matter, UCBB procedures, UCBD policy or the mere existence of UCBB initiatives. The various approaches to discern the level of awareness and knowledge in samples across a range of studies led to two different routes of inquiry: how should UCB knowledge be measured and how much UCB information is sufficient to induce desirable UCBC rate? These two questions encompass the contemporary gaps in research. This could be partly due to the fact that researchers mainly used surveys in these studies. As the surveys relied heavily on self-reported levels of knowledge, which could be at risk of bias. Participants may not know how to truly gauge their UCB knowledge and may downplay their abilities (Choy 2014). Interviews could have perhaps allowed for a clearer way of ascertaining participant knowledge as researchers can use their own observations to discern knowledge levels. However, interviews can be impractical due to the vast sample sizes seen in some studies.

Many studies that aimed to comprehend the level of UCB awareness across diverse contexts did not cross reference their results to UCBC rates. Shin et al. (2011) in Korea attempted to correlate knowledge level with UCBD among well educated, high-potential donors (863 pregnant women). However, rather than observing the resulting UCBC rate, they gathered attitudes towards UCBD in a hypothetical matter. Few studies attempted to measure donation rates based on knowledge (Grieco et al. 2018; Sward et al. 2019). Sward et al. (2019) aimed to complete an interventional study on physicians' UCB recruitment and collection practices in three different hospitals in the USA. They separated the sample and provided different interventions for each group. The group of HCPs that received one to one training and reflective journals collected more UCB units. However, the researchers did not measure the collection rates of the HCPs before the intervention, and therefore a baseline collection rate could not be analysed for comparison.

The overall findings regarding knowledge have now been outlined, however more there were more details found within this theme. The subsequent sections delve into these details and their impact on UCB collection.

### 2.3.2. Sources of knowledge

Out of the studies that focused on parents' perspectives of UCBD, UCBB, and UCBC (n=50), 17 of the articles examined parents' source of knowledge of public or private UCB collection. Only four of the 17 studies found that parents' first encounter with UCBB was through direct contact with HCPs or through leaflets from hospitals.

In India, Rajendran et al. (2018) conducted a quantitative study which investigated the differences in UCBD knowledge and factors impacting parents' UCB decisions. In their study, they noted that parents who received private care had been introduced to UCB and UCBB options via their HCPs and brochures, whereas parents in public hospitals were given less UCBB information from HCPs and were less aware of the processes. Rajendran's et al. (2018) study was a thoroughly conducted study, with rigorous methods and a large sample. While their sampling method (convenience sampling) can lead to debate regarding generalisability, the large sample size and varied location of participants aids in its generalisability (Taherdoost 2016).

From the HCP perspective, 10 studies observed the way HCPs were made aware of UCBB procedures. Sources of knowledge were through training methods and first encounters with UCBB in general. HCPs also declared the internet as their main reference for information. Patyal et al. (2018) conducted a study in India with 170 nurses, they assessed their awareness level of UCBB. The vast majority (94%) of nurses reported not having attended any UCB-related training courses. Similarly, two studies conducted in China and Egypt with the same aim, discovered that only a small proportion of maternity staff had received training on UCB related topics, 10% and 14.8% respectively (Lee et al. 2019; Mansour et al. 2020). Four of the 10 studies used interventional methods (i.e., courses, brochures) to enhance the midwives and antenatal nurses' knowledge of UCBB (Duffy et al. 2009; Mohammed and El Sayed 2015; Abdel Fadeel et al. 2018; Mansour et al. 2020). All the studies revealed a low level of knowledge prior to educational interventions, this increased upon the implementation of structured training programmes or provision of educational materials such as brochures. In the USA, Armstrong et al. (2018) found that only 11% of clinicians had received any form of education on UCBB, mainly during their residency. Similarly, in Japan, Tada et al. (2011) discovered that with regards to UCBC, 60.5% of obstetricians received no training at their institution.

Interestingly, the only study that revealed a high UCBB-related knowledge score found that 74% of midwives obtained their knowledge from the public institution for blood services in

Hong Kong. Popular health-related topics in the media are vulnerable to hype and exaggerated advertising of therapeutic potencies and advantages. Unofficial information sources may not be subject to quality control processes (Caulfield and Condit 2012; Macron et al. 2020). Also, they may lack transparency or peer review assessment, this implies that the information may not be accurate or based on scientific evidence (Peberdy et al. 2020b). Conversely in China, Lee et al. (2019) supported the positive correlation between training and the level of knowledge held by midwives. Those who had attended UCB training ranked significantly higher in their knowledge scores ( $P=0.009$ ) than those without. The source of UCB information plays a vital role and reflects the quality and reliability of knowledge held by HCPs on UCB. This may have an influence on pregnant mothers' decisions regarding UCB, in turn impacting the collection and inventory of UCB.

Scenci et al. (2012) conducted a study in Italy to investigate levels of UCB knowledge, preferences for UCB and private UCB, and the reasons for these choices using a sample of 300 expectant mothers and 1,000 blood donors. Scenci et al. (2012) found their sample was largely aware of UCB and 61% would opt to donate their UCB. Seventy-three percent of Scenci et al.'s (2012) sample opted for both public and private UCB to safeguard their future, signifying a level of trust in the overall UCB system. Scenci et al. (2012) aimed to explore UCB knowledge, attitudes, and intentions with regard to private and public banking. The main source of knowledge for this sample ( $n=298$ ) were HCPs in Rome, Italy. However, the findings cannot be said to be generalisable, despite the generous sample size, as the participants were recruited from the same institution, and it is likely that the hospital included UCB education as part of their policy. Nonetheless, the study based in Rome does highlight the fact that initial information about UCB should be given by HCPs, over 93% of the sample were aware of UCB and UCB and obstetricians were their main source of information (42%). Grano et al.'s (2020) study, in Italy, found that a high percentage (97.5%) of pregnant women ( $n=365$ ) were aware of the possibility of UCB, however, these participants were ill-informed about the procedural possibilities of UCB and UCB. In comparison with Scenci et al. (2012), the internet and social media (51%) were the primary sources of knowledge for Grano et al.'s (2020) participants (pregnant women). The two papers were based on a similar setting (Italy), with comparable sample sizes. However, the sample who obtained UCB information from HCPs had a clear understanding of the procedure of UCB and UCB, whilst those who obtained it from internet sources seemed to be more misinformed. In other cultural and geographical contexts, Jawdat et al. (2018) found that their sample ( $n=1146$ ) in KSA did not have sufficient awareness or knowledge of UCB

and UCBD (66%). Their sample cited social media as the first source of UCB information. Fourteen percent and 10% of participants surveyed had been introduced to UCBB and UCBD through hospital materials (i.e., brochures) or HCPs respectively.

This literature review revealed that training practices varied greatly across the field. Training provided to HCPs had seemingly led to misinformation and bias, which was passed on to parents or avoided UCB recruiting. From the parents' perspective, variation in hospital policy can be mapped also. Some parents were informed of UCBB through their hospitals, however most studies found that parents' first encounter with UCBB was through social media, internet, and mass media. This led to gaps in knowledge and misinformation. One of the areas of misinformation seemed to have been rooted in the private versus public UCBB argument, this is explored later in the chapter.

### 2.3.3. Factors affecting knowledge of UCBD and UCBB

#### 2.3.3.1. Education level

Additional and compounding factors seemed to correlate with the level of knowledge and awareness parents displayed. Eighteen percent (n=14) of the studies looked at parents' education level and its strength as a factor, which influenced their knowledge and awareness of UCBB options (both private and public). The majority (n=14) of papers revealed a significant correlation between parents with higher education experience and knowledge of UCBB. Furthermore, some studies found a positive correlation between higher education experience and a favourable attitude towards public UCB donation. This was the case in several Asian countries, such as Turki, Iran, and Lebanon (Tufekci et al. 2017; Azadpour et al. 2018; Saleh 2019).

Conversely, two Indian studies found no statistically significant correlation between pregnant mothers' educational status and their UCBB knowledge, awareness or attitudes (Vijayalakshmi 2013; Catherine et al. 2020). However, Vijayalakshmi (2013) paper omitted reliability and validity tools and lacked information regarding the survey method, as a result their findings could be biased and may need further corroboration.

In Rajendran et al. (2018) study, they found that parents with a higher education and from a wealthier socioeconomic background were more likely to donate. This paper, similar to Vijayalakshmi (2013) and Catherine et al. (2020) studies, was conducted in India, but in different cities. However, the research methods used by Rajendran et al. (2018) leads one to conclude that their findings are more valid. Rajendran et al. (2018) study had been more



rigorous and outlined the validity and reliability of their tools. The findings of Fox et al. (2007) did not, however, agree with Rajendran et al. (2018). Fox et al. (2007) found that pregnant women in their study, regardless of their level of education, displayed insufficient UCBB knowledge. This study was conducted in 2007 and at that time there was a general lack of understanding and awareness of UCBB worldwide (Williams 2018). More recent studies conducted after 2010, when UCBB was popular and many countries started their own UCB banks, may provide more contextually accurate results pertaining to knowledge or awareness. Articles written by Ginori et al. (2015) on midwives, Salvaterra et al. (2010) on midwives and obstetricians and Mistry et al. (2018) on obstetricians may be a more accurate reflection of HCPs knowledge of UCB collection and donation.

#### 2.3.3.2. Income Level

Some intersectionality was observed with regard to education, income and location of parents and their likelihood of having some knowledge of UCBD and UCBB. Studies that measured the correlation between income and UCB knowledge were fewer in number in comparison to education (n=6). Four studies deduced that participants from economically wealthier backgrounds were more likely to be aware of UCBB and UCBD or to have knowledge of UCB (Matsumoto et al. 2016; Rajendran et al. 2018; Saleh 2019; Zomer et al. 2021). Two studies with comparable sample sizes conducted in India, found no correlation (Vijayalakshmi 2013; Catherine et al. 2020).

Catherine et al. (2020) aimed to define the relationship between pregnant mothers' background demographic data (income, location, education), their knowledge of UCB and their likelihood to donate. The researchers recorded that 75.7% of the mothers had insufficient UCB and UCBD knowledge. This study contrasts with the findings of Rajendran et al. (2018) in India, which discovered a statistically significant correlation between income background and UCB and UCBB knowledge in their sample (n=428). Both studies were conducted in India, using similar sampling methods of non-probability convenience sampling. However, there is a vast difference in the sample size, Catherine et al. (2020) surveyed 70 pregnant mothers, whereas Rajendran et al. (2018) surveyed 428 mothers. Additionally, Rajendran et al. (2018) recruited participants from two different cities whereas Catherine et al. (2020) sampled from one institution. Therefore Rajendran et al.'s (2018) study gives a more balanced view of the situation in India.

### 2.3.3.3. Parents' Location

Few studies (n=4) examined parents' awareness or knowledge of UCBB in relation to their area of residence. All four of these studies demonstrated a correlation between the parents' home and the extent of their UCBB knowledge (Jordens et al. 2014; Rajendran et al. 2018; Saleh 2019; Szubert et al. 2020).

Saleh (2019) used questionnaires to test expectant mothers' attitudes and knowledge of UCBB and UCBD in Beirut, Lebanon. Those living in urban areas were more likely to know about UCBB than participants from rural backgrounds. The generalisability of the findings is limited by the fact that recruitment was from a single city and all the women already had one child.

Jordens et al. (2014) was conducted in New South Wales, Australia, where UCBB is more established. They examined UCBB awareness in women from different backgrounds. Using purposive sampling methods, 1873 expectant mothers were asked about UCBB and UCB. Jordens et al. (2014) asked participants what UCB is, its uses, how one would donate UCB and how it is stored. Jordens et al. (2014) noted that 44% of their sample were misinformed with regard to private and public UCB collection. They also concluded that participants from remote regions and those who did not speak English were less likely to be aware of UCBB. The study design used by Jordens et al. (2014) seemed to be more thorough in their aim to find correlation between location and UCBB knowledge. Although purposive sampling was used, the questionnaire was undertaken in governmental and private health facilities located in remote and urbanized areas. Interestingly, the sample's demographics matched those of the overall population of expectant mothers in New South Wales.

As parents' background and contextual conditions are likely to be a factor in decision making regarding UCB donation, the elements impacting on UCB knowledge should be clarified. In this literature review it can be surmised that education, location, and socioeconomic backgrounds can impact upon an individual's knowledge of UCBB. These factors provide a necessary basis for the adaptation of recruitment methods. The mothers that give birth in this study context came from varied regions. Although the PHMD is based in a major city and garners parents from cities, many people travel in from surrounding rural areas. These articles therefore provide relevant viewpoints on demographic traits of parents and whether they are likely to be aware of UCB donation.

#### 2.3.4. Attitudes towards UCBB

Thirty-one articles explored attitudes towards UCBB, and all that it entails, to some extent. While the majority of studies utilised surveys, the questions posed to participants varied at times. Some studies determined parents' attitudes towards UCBB by asking them if they planned to donate, this was the case in several countries, such as, Turkey, Lebanon, and Brazil (Tufekci et al. 2017; Saleh 2019; Zomer et al. 2021). Meanwhile Lee et al. (2019) ascertained midwives' attitudes in China by asking their opinions on the value of UCBB and its importance in the healthcare system. Further, some researchers from the UK and Egypt used experimental methods to ascertain participants' attitudes to UCBB (Duffy et al. 2009; Mansour et al. 2020). The various modes of attitudes were then compiled, including those studies in which participants were asked their thoughts on UCBD and UCBB. The context of articles and participants' perspectives were then assessed to discover parents' and HCPs' general attitudes towards UCBB, and donation.

Zomer et al. (2021) was one of the studies that revealed a negative attitude towards UCB donation among parents. They surveyed their Brazilian sample (n = 387) to discern UCBB knowledge and belief. This study went a step further in their research to ascertain the donation rate amongst their sample. Here, the number of participants who chose to donate their UCB to public banks is reflective of their attitudes towards UCBB. Half of their sample did not donate UCB, and when queried, 35% attributed this decision to a lack of awareness. This decision was predictable due to the size of the sample which was approached for consent. Only 14% of the sample recalled being asked to donate UCB, with 75% being approached for private UCBB rather than public. This section highlights the direct link between attitudes to public UCBB and individuals' knowledge and perceptions of UCBB, as well as the source of knowledge. This article however does not give information on the attitudes of the participants who were approached by HCPs, this would have given a well-rounded view of their findings. In Croatia, Matijević and Erjavec (2016) found that parents who received unbiased information regarding UCB, with emphasis put upon the altruistic value of UCBD, led to mothers displaying a preference for public UCBD.

Furthermore, 40% of the doctors in Tuteja et al. (2016)'s study in India expressed a desire to opt for public UCBD for their own children. However, Tuteja et al. (2016) did not attempt to further their research by exploring relationships between doctors' advice and parents' attitudes towards UCBB. In fact, much of the doctors' responses regarding UCB subject

knowledge were incorrect or inaccurate, this may be the underlying reason for the small number of HCPs that approached their parents with UCB information.

Szubert et al. (2020) aimed to evaluate the changes in UCB knowledge in Poland. Their sample size was 12,066 pregnant women who were surveyed in 2010 and again in 2017 to see any changes in UCB knowledge, it also asked for their perceptions of UCBD and UCBB. Participants were recruited using random sampling methods, and their demographic information given. Forty one percent of the sample came from rural areas, and the remaining 59% came from urban areas. While Szubert et al. (2020) found 49.4% of their sample considered UCBB useful, this number dropped slightly when women were surveyed in 2017 to 48.1%. This led one to conclude that the information given by HCPs was paramount to the attitudes of parents. This was due to the decline in HCP-led patient education on UCB in the same area (Hatzistilli et al. 2014). Though the findings show a less positive attitude towards UCBB, it must be highlighted that this study was not only on UCBB but also on further genetic tests for pregnant women. Therefore, information specifically about UCBB awareness and attitudes was unexplored. In addition, the methods of discerning mothers' awareness of UCBB did not include UCB-related questions and were on the knowledge of the possibility of UCBD instead.

Focusing on HCPs, Lee et al. (2019) explored midwives' UCB knowledge and attitudes in China. To do this, they surveyed 147 midwives using convenience sampling methods, the sample represented more public hospital staff than private. Overall, midwives' attitudes to UCB were positive with 91% of the sample reporting that UCBB was inherently charitable and valuable for the community. Lee et al. (2019) did not simply focus on participants' perceptions but observed the sample to see their recruitment practices. Midwives were not tasked with asking mothers to donate UCB, and this action was solely voluntary. Although the sample overwhelmingly agreed on the charitable and worthy nature of UCBD, only 10.9% gave information on UCBB to parents, and 7.5% attempted to recruit mothers for UCBD. The discrepancy between attitudes and practice can be elucidated further, the sample attributed their inaction to the added workload of recruitment, obtaining consent and collection procedure.

Mistry et al. (2018) aimed to assess obstetricians' knowledge, as well as mothers, and their attitudes towards UCBB. This study, conducted in two cities in India, randomly sampled mothers (n = 100) and obstetricians (n = 100). The attitudes described in this article contrasted with those seen previously, in this sample 4% of mothers were willing to donate

UCB and obstetricians displayed inaccurate knowledge of UCB. Pertinent findings noted by the authors were that 5% of parents were unwilling to donate due to religious reasons. The participants who refused on religious grounds were Muslims, they believed UCBD was not permissible in their faith. UCB is permissible in Islam, therefore it is possible that a more accurate reason for this negative attitude to UCBD is misconception. Mistry et al. (2018) sample cannot be generalised, due to the small sample size. Statistical tests were not included, thus, the significance of the results is in question. In addition, the participant characteristics were not diverse with regard to significant factors in UCBB knowledge (i.e., urban or rural, education level, income). The study did not conduct a statistical analysis of their findings, correlation between parents' knowledge (76% insufficient knowledge) and their attitudes could not be deduced. Although it can tentatively be argued that is the main reason for the negative attitudes of their sample.

Mansour et al. (2020) also aimed to discern nurses' attitudes towards UCBB through an experimental method to measure any changes in attitudes of nurses in Egypt. They sampled 128 nurses using purposive sampling methods, these methods are at times critiqued as being in jeopardy of researcher bias due to their participant choice (Etikan et al. 2016). Nevertheless, the authors used statistical analysis and rigorous validity and reliability tests, thus their findings were deemed adequate to add to the findings of this review. Mansour et al. (2020) aimed to see if an educational programme would influence nurses' views on UCBB. The percentage of HCPs who viewed UCBB as positive post-intervention, increased from 34.3% pre-intervention to 58.83%. This provides a concrete link between UCB knowledge, and attitudes to UCBB.

#### 2.3.4.1. Altruism

In total, seven studies found altruism to be a motivating factor for parents and HCPs to continue with UCBB. Duffy et al. (2009) surveyed a sample in an interventional study in the UK, they found that midwives in their sample considered it important to highlight the altruistic nature of UCBD. Duffy et al. (2009) sample felt that UCB collection could be burdensome due to the added workload. In Korea, Kim et al. (2015) asked new mothers if they had consented to UCB collection, if so, did they choose to donate to public banks or to store at private banks. They found that the majority (55.3%) of the mothers chose to discard their UCB, 34% chose to privately store their UCB, and 10.6% chose to donate (sample n = 320). This finding was surprising, as other studies such as Lee et al. (2019) in China, commented on the deep connection between collectivism and the desire for individuals to

be altruistic. Kim et al. (2015) aimed to understand mothers' knowledge and awareness of UCBB and UCBD in Korea, and their sample viewed altruism differently. Kim et al. (2015) found their participants preferred to store privately should family members need UCB therapies. Thus, these mothers viewed altruism as serving their wider family, rather than the community.

Katz et al. (2011) identified the knowledge levels and attitudes to UCB displayed by parents in five countries: France, Italy, Germany, Spain and UK. Their large sample (n=1620) was asked about their attitudes to UCBB and their motivations for UCBB. Overall, across the five countries, the researchers found a strong inclination for public UCBD. Eighty nine percent of the sample said that they would donate UCB. In addition, when asked for their motivation for this decision, 59% of the sample stated altruistic purposes. This hypothetical commendation for UCBB was perhaps surprising, as the majority of the sample stated they had insufficient UCB knowledge (79.4%), however it seems the participants knew the nature of UCB therapies and interventions.

In the studies that mentioned altruism, it seems that it was a surprise discovery rather than an area of focus. Despite this, the altruistic element of UCBB cannot be ignored as it could be a motivating factor for expecting mothers and HCPs alike.

### 2.3.5. Socio-Cultural Factors Impacting UCBD and UCBC

Elements of sociocultural factors impacted on attitudes and knowledge and were therefore included in those sections. In this segment, other impacts of sociocultural entities are explored. Elements such as family construct, influence and male dominance are explored further. This section now covers sociocultural factors which impact on UCBD and UCBC. The articles categorised in this section (n = 12) all examined the role of cultural and societal norms that impeded or motivated UCBD and UCBC. Some observations were made earlier in the chapter regarding ethnicity, sociocultural and socioeconomic factors, and their impact on knowledge. It was seen that participants from wealthier backgrounds, with higher education and from urban areas were more likely to have knowledge of UCB, UCBB and UCBD possibilities. These articles, however, investigated the impact of societal constructs on knowledge. In this section, studies demonstrate direct links between sociocultural norms and expectations and the aversion or preference for UCBB, with the focus on UCBD.

### 2.3.5.1. Religion

Out of the 75 studies selected for the literature review, only five studies mentioned that religion had an impact on participants' choices regarding UCBD. In Australia, Jordens et al. (2012) asked a group of six religious' scholars from various faiths (Catholicism, Anglicanism, Islam, Hinduism, Buddhism and Judaism) to comment on their faith-based views of UCBC. This study provided much insight on barriers and facilitators for individuals, given that citizens of the KSA are strongly motivated by Islamic laws and rulings. The scholars commenting on the Abrahamic faiths' stance mostly agreed with the promotion of public UCBD to the general population. As KSA holds a largely Muslim population, the Islamic scholar's comments were a point of interest. The Muslim scholar argued that public UCBD was more favourable in the religion, although private storage was also deemed permissible.

From HCPs' perspectives, results from Abdulrazeq et al. (2020) study gave insight into what obstetricians thought were impacting UCBC. Their sample consisted of 96 obstetricians recruited through purposive sampling methods in nine different hospitals across Jordan. Obstetricians were recruited from nine hospitals, with an overrepresentation of those coming from private hospitals (n=6) as opposed to public hospitals (n=2) and one university hospital. Although their sampling technique was susceptible to bias, their findings were of interest to this study as it was based in Amman, Jordan, therefore some similarities in culture and religious views could be expected. Through survey and demographic analysis, the authors found that over half (56%) of their parents surveyed perceived religion as a barrier for UCBC. Unfortunately, qualitative data on the parents' views were not collected, therefore this could not be corroborated. The overrepresentation of the private sector in this study could have had an impact on the practical procedures and knowledge of their parents. The demographic information revealed that all the obstetricians who regularly collected UCB came from private hospitals. The researchers suggested that this could account for the disparity in parents' knowledge in private and public hospitals. This could be due to the fact that private hospitals are furnished with educational materials from private banks to facilitate this education and appointments in private hospitals are longer and clinics less pressured (Abdulrazeq et al. 2020). Despite these critiques, the findings of Abdulrazeq et al. (2020) study is an important one, it further highlights the disparity between individuals attached to private and public hospitals. There is also a difference in the overall positive attitudes to UCBC in HCPs and relatively low self-professed collection rates (15.6% of the sample were regularly collecting UCB units).

For parents, religion is one of the reasons for their refusal to donate UCB. Meissner-Roloff and Pepper (2013) evaluated mothers' knowledge and attitudes towards UCB in South Africa, they found their sample had an overwhelmingly positive attitude towards UCBD and thought it useful. However, only 2.5% of the sampled 217 mothers refused to donate in this study. When asked for their reasons, parents cited religion or cultural reasons for their refusal. The study did not elaborate further on the small sample that had refused on religious and cultural grounds. Other studies attempted to understand the link between parents' faith and the impact it may have on decisions regarding UCBD. This link, however, was unfounded in a few studies conducted in various countries (e.g., Vijayalakshmi 2013; Catherine et al. 2020; Zomer et al. 2021). While in Nigeria, John-Olabode (2020) reported that the majority of their sample (mothers, n=400) did not feel that religion could impede or motivate their decision regarding UCBD (65.1%). However, despite this, the researchers found a positive correlation between religion and the desire to donate UCB ( $p < 0.05$ ). Thus, the researchers found that religious beliefs could be an intrinsic motivator for mothers.

There does not seem to be a consensus in the literature regarding the impact of religious beliefs, three papers found no link between UCBD and religious values whereas other studies saw a small number of participants cite it as a barrier. As this area has not been explored more deeply, it cannot be surmised whether religion acts as a barrier or a facilitator to UCBC. However, in Jordens et al. (2012) study, Catholicism, Anglicanism, Islam, Judaism, Hinduism, and Buddhism all recognised the benefit UCBB can bring to local communities, and more importantly, the legitimacy of the procedure in accordance with their laws.

#### 2.3.5.2. Family

Some papers (n=7) examined the way that participants' ideas about family constructs influenced UCBD. These studies could be categorised in two parts. Firstly, a theme seen in a small number of articles was that private UCBB was preferred by some participants, it was seen as a means of safeguarding the family should it be required (Parco et al. 2013; Kim et al. 2015; Rajendran et al. 2018; Saleh 2019).

In Kim et al. (2015) study, it was shown that despite the collectivist nature of the wider society in Korea, mothers were more willing to privately store UCB rather than donate publicly. This suggests that they prioritised the use of UCB within the family over donation.

Panasiti et al. (2020) explored the dichotomy between collectivism and individualism in UCB private or public banking amongst mothers in Italy. Their study defined the links between social altruism and the probability of UCBD. Overall, they found that participants who were



more altruistic and socially distant were more likely to donate UCB. Panasiti et al. (2020) defined socially distant individuals as those who do not principally spend time and resources on close family members. Conversely, participants who showed greater generosity towards family members were less likely to partake in UCBD. The findings of Panasiti et al. (2020) and those of Kim et al. (2015) show some similarities. Ultimately, when participants were socially close to family members, albeit measured in varying forms, private UCB storage was preferred.

Rajendran et al. (2018) found that families which could be described as a joint family, such as a blended family of stepparents or stepchildren, preferred private UCB storage. Although this finding was not found to be statistically significant, it was an interesting result which could benefit from further research. This finding showing that nuclear families were more likely to donate did not answer their research aims, therefore little discussion was given to the result. The reason for the variation between the two-family constructs may provide added information on how to approach parents for public UCBB.

In Matsumoto et al.'s (2016) study in Jordan, some mothers refused to donate if their husband had not given them permission to do so. As this study context is based within a similar culture, it was an important finding to note. Additionally, in KSA, Jawdat et al. (2018) found that mothers would not donate without their husband's consent.

In this PhD study, KSA is considered a collectivist society because of religious teachings and the society's strong connection to religion. The expectation was that collectivist societies would donate UCB more readily than individualistic ones. On the other hand, family and family values are also highly regarded, this suggests that there may be a preference to keep UCB for private use even though this is not an option in KSA. The literature is divided on this, and it is unclear whether collectivist societies are more likely to donate UCB units or prefer to keep them for their own extended families, as shown by Kim et al.'s (2015) study.

### 2.3.6. Bureaucratic and Organisational Barriers

In this literature review, inaccurate knowledge, and a lack of awareness of UCBD procedures were established as barriers to UCBD. This has been documented in previous sections. Research which has focused on parental, or HCP knowledge and awareness seemed to view decisions about UCBD and collection as wholly individual barriers. Some studies aimed to view UCBC procedures through a wider lens, opting to shed light on bureaucratic, organisational, and physical entities that obstruct optimal collection rate. In total, nine studies gave information on these macro level barriers.

### 2.3.6.1. National level

In this section, bureaucratic barriers include barriers that affect the entire healthcare field or professions within the country the examined study. Thus, when a study, based in China, describes the difficulties HCPs face in regularly informing parents of their UCBB options (Lee et al. 2019), the same cannot be assumed for Italian studies.

In Italy UCBB information is regularly given through various mediums as UCBD is prioritised in the Italian healthcare system (Sacchi 2018). Out of the nine studies that explored barriers on a macro scale, four of those found some evidence of bureaucratic barriers in their study settings. One such study by Lee et al. (2019) surveyed midwives from various government obstetric clinics, private and public hospitals (n=147) to assess their knowledge and attitudes towards UCBB. Their knowledge of UCBB was relatively high (77% of the sample showed adequate UCBB knowledge) and attitudes were overwhelmingly positive (94% positive attitudes). Despite participants' perceived motivation, which would lead to the deduction of stable collection rates, only 10.9% of participants reported that they gave parents information on UCBB, and 7.5% encouraged parents to donate. This may link with the amount of training participants had received, 10.2% of the participants reported that they had been trained in UCBB recruitment. Training was not widely incorporated, and midwives felt that they were inhibited by the lack of formal policy. This finding could pinpoint the necessity for both individual motivation, such as knowledge and awareness, as well as institutional shepherding, through regulated protocol.

Conversely to Lee et al. (2019) study, other studies showed bureaucratic factors that allowed for participants to partake in UCBD. Parco et al. (2013) explored the motivation behind pregnant mothers' choice of public or private UCB storage. In their Italian sample (n=722) they found that 84% of their sample chose UCBD. Interestingly, in Parco et al. (2013) as well as other Italian studies (Screnci et al. 2012; Grieco et al. 2018; Grano et al. 2020) mothers seemed to be more aware of UCBB than those from other countries.

This led to further research of public health policy in Italy to establish whether there is strong infrastructure regarding UCBB. Italian national health policy has prioritised the maintenance of a substantial reserve of UCB units (Sacchi 2018). William's (2018) article explores the importance of strong bureaucratic decisions regarding UCBB and collection to fortify individual hospital policy on UCBC and overall collection rates. William's (2018) argues that individual UCBB should be viewed as part of an overriding infrastructure, where maintenance and upholding policies are key to ensuring the strength of UCBC. From this literature review

it became clear that Italian public policy, to uphold, maintain and prioritise UCBC, has resulted in accurate information being regularly given to prospective parents. Therefore, the Italian model of UCBC from a wider lens is one that countries may want to adopt. However, before this conclusion can be drawn, research to explore the effects of Italian policy should be undertaken.

#### 2.3.6.2. Organisational level

Some barriers can be seen as singular to the organisations to which participants belonged. These hospital-based barriers were defined as organisational barriers. In India, Gupta et al. (2019) conducted a cross-sectional study, they surveyed HCPs to assess obstetrician's knowledge, awareness, and attitudes towards UCBB and their expectations. This study surveyed 154 obstetricians through convenience sampling. They found positive attitudes towards UCBB, and the majority of the sample (74%) reported the need for more training. In this sample, the participants were recruited using convenience sampling methods from three hospitals within the same region in South India. However, convenience sampling methods can be disadvantageous for generalisation, the findings can be based on biased data. If the assumptions are to be founded on more reliable data, randomised sampling methods should be used to gain an understanding of the organisational aims of the hospitals in that region for future work. Despite these pitfalls in the sampling method, Gupta et al. (2019) reported the need for organisations to encourage HCPs to collect. Fifty-seven percent of the sample felt that monetary incentives could act as motivation for collecting UCB. This paper highlights some of the ways organisations could implement procedures to induce higher rates of UCBC.

Machin et al. (2012) examined the relationships between parents, midwives and private UCBC staff (phlebotomists) and the power balance in UCBC maternity wards in the UK. They surveyed 61 participants using purposive sampling. When exploring the power dynamics between two HCP teams by observing the structure of time and space occupied by teams. They found that midwives held authority in maternity wards because they considered it to be their space. In turn, phlebotomists felt they did not have the autonomy to carry out UCB collection during labour, as they were not in their space. However, this imbalance in power shifted when phlebotomists felt empowered by mothers who advocated for them, as they were paying to collect and store their UCB. Although this study focused on the dichotomy of power between external private UCBB phlebotomists and NHS midwives, this paper was included in the review as the partnership pertained to this study's aims. In KSA, UCB collectors were a different team, employed by an external UCB bank, working on a maternity

ward occupied by midwives. This paper speaks to the impact organisational oversights can have on partnerships between such teams and the power imbalance that occurs due to a lack of boundaries set by organisations. Thus, this paper gives necessary insight to partnerships in UCBC.

An expected barrier was that of bureaucracy for HCPs and parents alike, however only two studies found the paperwork and consent taking process an issue in their samples. In this review, the term bureaucracy is used to describe the paperwork processes of UCBB and UCBD. For parents, Shin et al. (2011) asked parents from wealthier backgrounds in Korea, these groups were assumed to have higher affinity for UCBB, about their attitudes and intention for UCB and the reasons behind it. One compelling argument made by parents was the length of the consent process and the medical questionnaire. This study recruited a large sample from one hospital base (n=863). Thus, this may highlight issues with the hospital's consent-taking process. Mothers felt the paperwork process should be smoother, given the stressful time of labour. As this study focuses on women from urban backgrounds with higher income than the national average, it cannot be said that this finding is applicable to the participants in this study. However, it does speak to the ways in which parents are recruited for UCBD.

In addition, organisational efforts to improve knowledge about UCBB were not always successful or evident. Abdel Fadeel et al. (2018) conducted an interventional study to improve nurses' attitudes towards UCBB by providing educational literature for HCPs from two hospitals in Egypt. Although other studies' intervention tools were more thorough, using workshops and training sessions (Sward et al. 2019), Abdel Fadeel et al. (2018) found some notable results. Firstly, it seemed that despite the intervention, many of the staff were still under some misconceptions, mainly that public UCBB could be done at a cost to donors. This misconception was also seen in Armstrong et al. (2018) study, where HCPs in Chicago children's hospital did not have knowledge and were not trained on UCBB.

Another organisational barrier is the policies and directives in place to support UCBC. In Abdel Fadeel et al.'s (2018) study, 78% of the nurses felt that the hospital's policies did not allow for UCB collection. In agreement with the parents surveyed in Shin et al. (2011) study, 38.5% of nurses felt that the point at which consent is sought and the bedside information given on UCBB is inappropriate. In the two hospitals in Abdel Fadeel et al.'s (2018) sample, no UCB related education was provided during antenatal appointments, this was also the case for contextually different studies (Armstrong et al. 2018).

As the two sites used in Abdel Fadeel et al.'s (2018) study are from the same region in Mina, Egypt, this finding cannot be deemed as appropriate for the wider population due to the convenience sampling method. However, the study does reveal clear pitfalls to be avoided for further UCB programmes, such as bedside recruitment at the time of labour. Grieco et al. (2018) also conducted an experimental, interventional study, in an obstetrician-gynecologist clinic in Italy. They evaluated changes in attitudes and decisions made on UCBD by parents who have received education sessions from the researchers. Their large sample (n=850) consisted of pregnant women undergoing treatment at the clinic. The researchers followed up with participants to find out who eventually did or did not donate UCB, and the reasons for their decision. A hundred and forty mothers refused UCBD, 30.3% of these mothers noted that it was due to organisational difficulties such as the absence of UCBC staff to collect the units and overcrowding of the delivery room.

#### 2.3.6.3. Workload

A result that was not explored in depth was that of the additional workload created by UCBC. Only five studies showed results in relation to workload (Duffy et al. 2009; Bhandari et al. 2017; Haw et al. 2019; Abdulrazeq et al. 2020; Haw et al. 2020). Both Abdulrazeq et al. (2020) and Duffy et al. (2009) reported that UCBC did not add to their HCP participants' workload. Bhandari et al. (2017) found that time was a barrier for HCPs they surveyed, also indicating workload issues which inhibited collection. Around 40% of the sample reported the lack of time as a major barrier for collection.

Haw et al. (2020) demonstrated an understanding of the emotional labour that UCB staff felt in UCBC sites in Canada. They conducted interviews with 15 HCPs, one of the few qualitative studies found in this review. They found that increased workload was felt due to heightened sensitivity and emotional labour. At first participants felt that recruitment required soft skills and non-verbal communication to incite positive attitudes towards UCBD. The second instance of heightened emotional labour was recorded during collection times, where UCB staff reported the importance of being sensitive to the atmosphere in the delivery room. They often felt that they had to adapt themselves in any given situation, be it the joys of birth or fraught situations due to traumatic labour. Although this study gives much needed information on the added pressures on UCB teams when collecting UCB, other policymakers' thoughts on the conduct of UCB nurses may have been useful. Despite this, the findings of Haw et al. (2020) describe the importance of including emotionally intelligent staff as UCB nurses, with experience in reading the room and acting accordingly. Nurses reported the

responsibility they felt to ensure enjoyable moments for mothers, and that UCBD should not impose any risk to mothers.

Haw et al. (2019) study aimed to understand the motivation and barriers to UCBC from a wider context. They followed a qualitative case study design, 15 UCB nurses were interviewed to obtain their views on the factors which impact on UCBC. They found that organisational factors, such as reduced UCBC hours, led to increased workload as UCB staff tried to maintain collection rates despite the shorter working day. They also found that there was a higher perceived workload, particularly in recruitment, when staff encountered mothers whose first language was not in their area of expertise (English, French, Punjabi and Chinese). These findings differ to those of Abdulrazeq et al. (2020) and Duffy et al. (2009), perhaps due to the method of discerning workload. Within Haw et al.'s (2020) study, workload included emotional labour, whereas Abdulrazeq et al. (2020) and Duffy et al. (2009) did not. Hence, while Abdulrazeq et al. (2020) and Duffy et al. (2009) found that UCBC did not add to the workload of UCB collectors, Haw et al.'s (2020) study found that UCBC added workload for the UCB nurses, perhaps in the form of emotional labour.

### 2.3.7. Facilitators

In previous sections, factors that affected UCBC were explored, and some facilitators were observed and commented on. These facilitators were revisited in this segment, to combine valid facilitators that had been found as well as others found in studies and not yet explained.

From a micro-level perspective, facilitators explored earlier relate to the factors affecting an individual's motivation for donating. For example, some articles found that altruism was a significant factor in parents' decisions to donate UCB (Porter et al. 2012; Matsumoto et al. 2016; Panasiti et al. 2020). As well as the correlation found between some studies, investigating the correlation between knowledge and awareness of UCBD and donation rates, although few studies defined that link (Grieco et al. 2018). One example was found to contrast with barriers, as in many of the findings found above, factors could act as both facilitators and barriers in varying studies. The same barrier found in Lee et al. (2019) study described HCPs' low collection rate despite their positive attitudes UCBD.

In contrast, Italian studies described how hospital policy (organisational facilitator) and a nation's healthcare priorities, such as UK's NHS, (bureaucratic facilitators) meant that parents were more likely to have knowledge of UCBB and a more positive attitude and intention with regard to donating. These facilitators manifested themselves in various ways, depicted in the barriers section of this review. For example, parents' first encounter with UCBB to be via HCPs

or medical brochures as their source of information (Screnci et al. 2012; Alexander 2014; Jordens et al. 2014).

Some studies reported that parents' individual traits and demographics led to a higher affinity with UCBD. Previous sections described how some studies reported that demographics such as education level, income and location had an impact on UCBB knowledge and donation decisions (Jordens et al. 2014; Rajendran et al. 2018; Szubert et al. 2020; Zomer et al. 2021). These areas seemed to be researched in greater depth. Here, studies that found additional factors which impacted on UCBB decisions were explored. Two studies found a significant correlation between multipara parents and UCBB knowledge and UCBD awareness (Karagiorgou et al. 2014; Saleh 2019). Although this finding is not found in more studies, this is an area of research that could greatly influence UCBD recruitment practices. It suggests that multipara mothers could be identified for recruitment as possible donors. To implement it in practice, however, further research must be conducted.

Another facilitator is previous experience of UCBD. This was seen in six studies, albeit experience differed across these studies. Some studies commented on the correlation between blood donors and UCBD intentions (Fernandez et al. 2003; Shin et al. 2011; Kim et al. 2015), while other studies looked at parents' previous experience with UCBD (Karagiorgou et al. 2014; Grano et al. 2020). Finally, Jordens et al. (2014) looked at the parents and their loved one's experience with transplantation, which could have been treated with UCB, such as leukaemia. Although not a necessary element of their aims, Jordens et al. (2014) found that there was a relationship between UCBB knowledge and personal experiences with transplant therapies. Karagiorgou et al. (2014) and Grano et al. (2020) both found a correlation between participants who had donated UCB and future decisions to do so again. Lastly, three studies looked for links between general blood donation and UCBD. Fernandez et al. (2003) found a link between general blood donation and UCBD, as did Shin et al. (2011). However, Kim et al. (2015) did not find the same correlation. Much of the findings seen in Kim et al. (2015) study seem to be particularly context based, their results often contrasting with their peers who investigated similar aims. Perhaps the differences seen in their findings is due to the importance of family in their sample. Nonetheless, Karagiorgou et al. (2014), Kim et al. (2015) and Grano et al. (2020) did not aim to understand the link between blood donation and UCBD, rather, they noted these observations within the variables they studied.

Other facilitators of UCB donation were found in studies, which are briefly highlighted in this section. Many of these findings are singular and have not been explored in numerous studies, therefore they are viewed as interesting research starting point.

Jordens et al. (2014), reported that accessibility of UCBB educational materials for parents was a facilitator. Although the only language option was English, this alienated non-English speaking parents in New South Wales, Australia. Following this theme of language, Haw et al. (2020) in their article explored the emotional labour experienced by UCB nurses in Canada, they found that their sample relied on their soft skills of positive communication to recruit mothers. In addition, their participants explained the necessity of hyper-vigilance when communicating with parents, their moods and progress of labour.

Some interventional studies attempted to establish the most appropriate time to approach mothers to inform and recruit them for UCBD (Armstrong et al. 2018; Grieco et al. 2018). In the USA, Armstrong et al. (2018) saw that HCPs who had received formal UCBB training had greater success in recruiting mothers and collecting UCB units of the desired quality. In addition, Armstrong et al. (2018) found that the best time for recruitment was during appointments in parents' third trimester. In Italy, Grieco et al. (2018) also found that the third trimester was the best time for recruitment, the researchers also included additional variables in their interventional study. They varied the type of information (one to one, or brochures) time of prompts, and the frequency of prompts. Grieco et al. (2018) found that introduction to UCBB and consent taking in the first trimester, followed by a second prompt and reevaluating consent in the third trimester was found to be the most effective form of recruitment. Moreover, the variations where mothers were prompted during the third trimester were more effective than those mothers who were recruited only during the first trimester.

### 2.3.8. Comparing UCBB practices in KSA with other countries

UCBC and UCBD practices differ across the globe. UCBBs are also situated differently within the healthcare system, this affects the way mothers are recruited for UCB donation and how UCBBs share resources.

In the UK, there are particular maternity facilities and hospitals that are associated with the NHS UCBB and permit public contributions. Several private banks operating in the UK provide private UCBB services. Mothers are only approached for possible public UCBD at maternity units that have a connection with the NHS UCB networks (William's 2018). This network is somewhat similar to that of the system in KSA. In KSA there are two public UCB banks, both



of these are located and administered by two different speciality hospitals (Jawdat et al. 2018; Shaheen et al. 2020). These two banks do not share inventory, but when neither has a UCB unit that is a perfect match for a patient on the stem cell transplant waiting list, they coordinate their efforts to find one. One of these banks is located in the National Guard hospital; however, it only collects UCB units from pregnant women who are eligible for healthcare at their facility. In contrast, the other UCB bank in KSA is the UCBBH, which targets mothers from several partner hospitals that serve the general public. Therefore, the UCBBH established alliances with three major hospitals that provide maternity care services, and mothers are approached to donate UCB after giving birth (Al-Haidar 2013). Currently there is only one maternity hospital which actively collects UCB units for the benefit of this bank. Whereas in the UK, there are three NHS hospitals which collect UCB and five other hospitals nationally, these are associated with the Anthony Nolan charity UCB bank, which also publicly collects UCB (NHS 2018).

By comparison, Italy has UCB banks which are available nationally. The public UCB banks in each region make up the regionally organised UCBB system. In order to potentially employ donated UCB units for transplantation or research, these local UCB banks attempt to collect and store the units (Sacchi 2018). The National Transplant Centre (Centro Nazionale Trapianti), which offers guidelines and standards for the collecting, testing, processing, and storage of UCB units, is responsible for organising and regulating UCBB in Italy. In KSA, the two UCBBs are regulated by the respective hospitals that run them.

Conversely, in Canada only four hospitals in four cities collect UCB for public donation (Haw et al. study). The four cities are Ottawa, Brampton, Edmonton and Vancouver. In Canada, a national drive to collect UCB took place more recently than in the UK, the first nationally owned UCB bank was opened in 2013 (Eggertson 2013).

In KSA, only public UCBB is available and parents who wish to store UCB for private use will have to do so outside the country. This is similar to Italy where there are also no private UCBBs. Private UCBB in the UK is available on the other hand. In KSA, Italy and in the UK, storage of UCB for public use is funded by the government and parents bear the cost for private UCB storage.

The people responsible for the collection of UCB also differs between countries. In the UK, midwives undertake UCBC in the participating hospitals. However, in KSA and in Canada, specifically appointed UCB nurses are responsible for facilitating UCBC. In KSA, midwives also support the UCB nurses in UCBC where required.

## 2.4. Chapter Summary

The majority of studies used surveys to focus on participants' knowledge, awareness and attitudes towards UCB, UCBB and UCBD. To summarise, in most studies parents were found to have insufficient knowledge of both UCB and UCBB initiatives. HCPs were seemingly, under-trained in UCBC and under-informed about UCB in general. However, attitudes towards UCBD were mostly positive.

There were gaps in research that could prove to be crucial for further intervention development. While most studies aimed to understand the links between attitude and knowledge, few investigated actual collection rates. Those that did saw a connection between knowledge and collection rates, however, the data collected was insufficient to conclude causality. In addition, thorough and purposeful research to investigate the tangible effect of sociocultural structures on UCBC rates was found to be lacking. In addition, larger organisational factors were mostly missing from the review findings. Organisational factors directly affecting collection teams or parents, for example, were not rigorously examined, with the exception of Haw et al. (2019) and Machin (2016). Rather, individual (micro) barriers and facilitators seemed to be investigated thoroughly. The contextual background of these micro barriers and facilitators were at times touched upon but were not investigated with the same rigour. Despite the gaps in literature, what became apparent was that there was an interplay at work, one which can impact on UCBD and UCBC. Micro (individual), meso (organisational and groups) and macro (national and societal factors) (Martikainen et al. 2002) barriers and facilitators were explored, and a summary of these findings are modelled below.

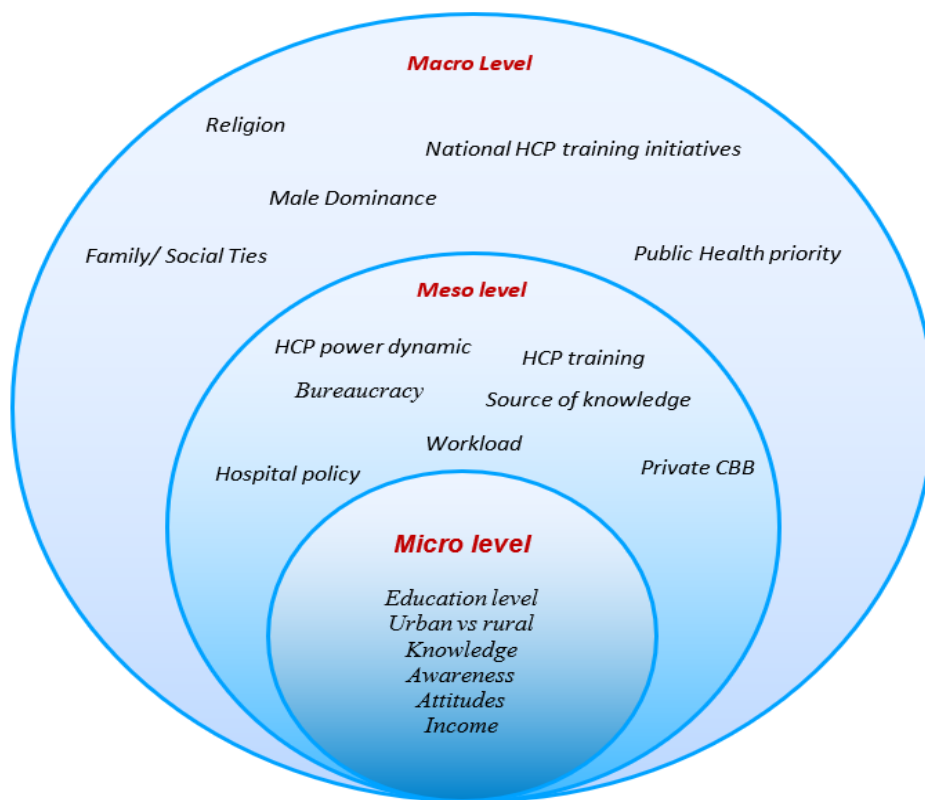


Figure 5. Issues concerning UCBC at micro, meso and macro levels.

Figure 5 shows the three categories that the factors impacting recruitment, negatively or positively, found in the reviewed data. The literature was analysed inductively in order to comprehensively identify barriers and facilitators to UCBD and UCBC, and the findings were then narrowed down. Using deductive analysis could have led to an unintentional rejection of vital findings. The model displayed above highlights the main findings of the literature review and the hierarchy in which they exist. Although wider concepts on the macro-level were scant, key findings were still found in this field. The model provides a foundation for future research and shows gaps at the macro-level. There was only one study examining UCBC in KSA and that focused on micro-level factors using a survey method (Jawdat et al. 2018).

Not only were there gaps in study content, but there was also an overrepresentation of quantitative studies in the findings. With most of the studies utilising surveys or questionnaires, few qualitative research studies had taken place. Qualitative research can provide a rich, contextual understanding of UCBB from various stakeholder perspectives, particularly in the KSA, due to the scarcity of studies in this field. Additionally, the use of CR as a research philosophy allows for those descriptions to be approached within the wider

context of Saudi society, healthcare partnerships and the establishment of public programmes. CR ontology denotes the necessity of looking at the whole when attempting to get as close to the truth as possible. The whole truth of UCBD and UCBC in KSA has not been explored in literature. As there is insufficient research in the context of KSA, it is not certain whether the points raised in the literature review can be made applicable to the context of public UCBB in KSA. This study can therefore aid in application to this new context.

## Chapter 3. Method and Methodology

### 3.1. Introduction

This chapter describes the philosophical and methodological positions of this study. Philosophical stances are articulated and have ultimately shaped the design of the study (Chia 2002). As established in the literature review chapter, the decline in UCBD and UCBC in KSA, and causes for the decline are not yet comprehended. The chapter begins by outlining the most prevalent research philosophies and subsequently the philosophical foundation of this study. Once these are outlined, the proponents of CR as a meta-theory that dictates the philosophical underpinnings are explored. This chapter defines the main tenets of a CR approach, how we understand the social realm and what its reality contains. Some of the main CR elements, including the stratification of reality and the interplay between structure and agency, were also addressed in this chapter. I sought to explain these tenets in light of the literature and determine the appropriate methodology for the study, whilst addressing the researcher's position.

Then, based on the philosophical foundations of CR, the analytical approach to the study (abstraction and retrodution) was explored. The arguments are presented to inform the analytic technique, and these can be found towards the end of the chapter. Nonetheless, the arguments presented in the CR literature provide a reasonable starting point that should be approached with caution, particularly by junior researchers such as myself. Finally, the analytical techniques are explored.

### 3.2. Philosophical Standpoints and Research Paradigms

To comprehend research philosophy, it is necessary to have some familiarity with research paradigms. Paradigm and theory, not only guide the process of study design, but also the analysis of findings. The term paradigm is used to define the perspective of a researcher (Mackenzie and Knipe 2006). A research paradigm is the basis for concepts built from a set of theories, beliefs, or assumptions. In other words, a research paradigm can describe the researcher's standpoint and observations of the world (Lincoln and Guba 2002). Epistemology, ontology and methodology are the three basic components of a paradigm. Having a definitive standpoint on those three elements is crucial to conduct research, as

these elements provide theoretical underpinnings, upon which the study design will be based.

Ontology and epistemology are generally accepted as the most central elements of research paradigms and philosophy of knowledge (Kivunja and Kuyini 2017). Briefly, ontology refers to reality perception and the nature of existence. It is about whether reality exists and what reality is (Crotty 1998; Al-Saadi 2014). For example, determining and differentiating conditions is an ontological consideration where doctors need to consider the symptoms of the disease and what the patients says (both of which can be considered different types of realities). In simpler words it is a component of philosophy that investigates the idea of existence itself. It studies the existence of things by asking questions such as, do things exist? If this is the case, what evidence supports its existence? What are the consequences of whether something exists? Ontology has been a subject of debate among different schools of philosophy. Secondly, epistemology is the second component of philosophical paradigms that denote the disposition and advancement of knowledge (i.e., how do we know things). It studies the origin, nature, and extent of human knowledge (Richards 2003; Al-Saadi 2014). It is concerned with epistemic justification as well as belief and thought rationality. Epistemology is concerned with how one knows what they know, and the questions that one asks oneself to get to the knowledge.

Methodology states the routes of data identification, collection, selection, and evaluation, within a research paradigm. It is the way in which a researcher seeks to reveal or discover what could be known according to what he or she thinks (Norton 1999). Each research paradigm has its own epistemology and queries regarding the theory of knowledge (ontology), the objectives of study (i.e., comprehension, explanation, or assessment) (Della-Porta and Keating 2008).

When carrying out a research, tangible processes such as data collection and analysis are often restricted by practical and ethical constraints. Nonetheless, philosophical issues such as data reliability or the veracity of either the participants' or the researcher's claims cannot be ignored and simply subsumed into the research activities (Maxwell 2012). For instance, an interview participant may or may not provide a genuine description of the studied phenomena. Nevertheless, the researcher should be concerned about the reliability of the participants' statements as well as the researchers themselves (Creswell 2013). This is to say, the key components of a paradigm are linked logically (i.e., ontology, epistemology, methodology). To suggest that philosophical considerations should not be prioritised is to

claim that some research steps such as validity and reliability are not fundamental to the researcher's work.

An exploration of the most common research philosophies helped with the selection of the most appropriate approach to meet the study objectives and answer the research question (Bhaskar 2013). It was particularly essential owing to the nature of this study design – qualitative research with various participant groups - which resulted in complex data. The study aimed to identify the possible factors which had led to a decline in the UCBD and UCBC rate. Also, it was essential to understand ways in which these factors influenced donor recruitment and UCBC according to the donor parents' perspectives as well as healthcare professionals. An appropriate philosophical perspective would help to draw discrete recommendations based on the study findings (i.e., barriers and/or facilitators). It can propose how the relationship between these rooted factors (mechanisms) may lead to a change of behaviour or practice within the UCBB practice. These recommendations could then be taken into consideration by the programme policymakers to optimise donor recruitment and CB collection processes. Lincoln and Guba (2002) argued, the chosen philosophical paradigm CR provided a foundation of base assumptions, which helped to shape the study and the researcher's standpoint, this would enable the researcher to answer the research question.

Table 7 below depicts three frequently cited paradigms in healthcare research (Gemma 2019): interpretivism, realism, and post-positivism (e.g., CR). The subsequent section provides an explanation of these paradigms, followed by a discussion of CR, the chosen research paradigm.

Table 7. Philosophical paradigms often used in healthcare sciences adopted by (Gemma 2019)

<b>Components</b>	<b>Post-positivism</b>  Such as Paradigm shift by Kuhn  and Critical realism by Bhaskar	<b>Interpretivism</b>
<b>Ontology</b>  (What is the nature of reality?)	Transitive and intransitive worlds. Transitive: is what we observe/learn with mind, the perceptions of reality. Intransitive: reality is independent of what the mind thinks.	Multiple realities exist, subject to human experiences and interpretation. Reality is socially constructed.
<b>Epistemology</b>  (How do we know what we know?)	<u>Modified objectivity</u>  Transitive world: changes continually. Intransitive world: has underlying structures/mechanisms are 'relatively enduring' – that is what we want to study.	<u>Subjectivity</u>  Knowledge generated is subjective, time-bound, context dependent. Constructed via researcher and objects interaction
<b>Methodologies</b>  (The strategic plan to extract the knowledge?)	Researchers attempt to analyse and reveal the latent or active structures and mechanisms that underpin subjective reality. Retrodictive reasoning. <b>e.g.</b> <ul style="list-style-type: none"> <li>• Critical realists' evaluation,</li> <li>• Action research</li> <li>• Dialectical critical realism</li> </ul>	Knowledge is generated via researchers' interpretations who usually seek patterns within collected data in order to constructs the exist reality. Inductive logic and emergent design. <b>e.g.</b> , Hermeneutics
<b>Data collection methods</b>	Quantitative, Qualitative, Mixed methods	Qualitative methods such as:  Interviews, Focus groups, Observations



### 3.2.1. Interpretivism

Qualitative studies often employ the use of interpretivism as the chosen frame of research philosophy. Interpretivism occupies one end of a virtual spectrum of knowledge paradigms, it recognises context as a major influential factor of observed phenomena (Clark 2017; Williams et al. 2017). While realist paradigms hold the view that a single reality is observable and empirical, Interpretivism asserts that there are several realities, each of which is intimately tied to the individual's social surroundings (Goldkuhl 2012). Reality is thought to be subjective, and unique to each person. Interpretivists believe that individuals are nuanced and complex. People perceive the same objective reality in many ways, and often they have very diverse reasons for their actions in their world (Tushnet 1982). Interpretivism is popular in qualitative research as it allows for the existence of contradictory observations.

Due to the assumptions of interpretivism named above, regarding the existence of reality, the aim of interpretivist research is often to focus on the individual and their perception of reality. No one reality can be used as typical and all the different realities are equally valid, though they may contradict one another (Wainwright 1997). These assumptions on reality do not align themselves with the aim of this study. This study aims to reveal and define the points of a UCBC programme that are beneficial or inhibitive to collection rates. The UCBC programme itself is a single reality that this research aims to better understand, from multiple perspectives. As such, this research is concerned with multiple interpretations of the same reality.

### 3.2.2. Realism

Realism positions itself as the opposing end of interpretivism. Essentially, realism's base assumption is that reality exists outside of the human perception of it (House 1991). Thus, there is a reality that can be deduced, and its components understood.

Scientific realism is one of the developed forms of realism that includes seen and unseen factors and their effects on what is being measured. Scientific realism depicts the world as independent from one's knowledge of its existence and acts in accordance with laws that can be deduced (Collier 1994). To them, reality is basically the world as described by science. Realists argue that attempting to observe unseen elements of the world, such as electrons or atoms is irrelevant, if we can make reliable claims about them and understand how they behave. Due to the many variations of realism, it is lengthy and complex to describe the nuances in the many variations of realism. As a result, a brief explanation of the distinctions

between scientific realism and CR will be provided. Following that, when referring to realism, the common tenets of realistic paradigms will be discussed from this point.

Outhwaite (1987) identifies beneficial techniques in the realism paradigm for focussing away from epistemology and towards ontology. Ontology from a realist standpoint, depends on the acceptance that elements which form our world are unobservable (Wainwright 1997). Bhaskar (1989) claims that all methods of knowledge organisation follow a form of realism in the way that the nature of existence or ontology is explained. The notion that reality exists outside of human understanding is a difficult concept to grasp.

When an investigation based on scientific realism or CR takes place, they do so within an open system where a variety of structures exist (Wilson and McCormack 2006). A world viewed through the lens of realism is made up of many different systems (i.e., psychological, physical and social systems) (Westhorp et al. 2011). Open systems suggest that there is fluid movement between the components of different systems (Westhorp et al. 2011). Both realisms aim to reveal and understand the structures and mechanisms leading to the phenomena under investigation. However, the dilemma according to Scambler (2002) is, if the physical world exists independently of human knowledge, how could the social world claim the same principle, given that individuals are a part of the world in which they live?

The emphasis on revealing causal structures, according to CR, is also applicable to the social sciences, through an understanding of the interdependent relationship between individuals and society (Wainwright 1997). According to Bhaskar (1979), the structure was always necessary for agency and at the same time, agencies reproduced or transformed structures. In other words, the structures exist prior to any round of human agency, people cannot engage in the speech act unless they have a pre-existing structure of language. Also, they cannot get married unless there is a pre-existing structure of marriage or family structure.

Therefore, to follow, believe and implement a realist paradigm, it is imperative to be committed to the existence of theoretical constructs. Realist researchers must believe that theoretical constructs such as black holes, atoms, electrons are as real as concrete observable objects such as hills, mountains, and oceans (Hacking 1983).

Realism offers a philosophical foundation for empirical research, it uses valid and reliable tools to quantitatively test, correlate, or assess the feasibility of various interventions. It seeks the understanding of social phenomenon through testing the proposed hypotheses to identify the most likely association patterns and the most reasonable explanation. This is

inconsistent with the current study aim, this seeks to gain a meaningful, thorough understanding of the study problem from varying perspectives in order to reveal the mechanisms which have caused a decline in UCBC rate in KSA.

### 3.3. Critical Realism

CR is one prominent example of post-positivism (Gemma 2019). CR is neither a development of positivism, nor anti-positivism. Instead, it is an alternative method to inquiry that attempts to reconcile the polarities of interpretivism and positivism. Thus, the CR exists on a spectrum between interpretivism on one end and positivism on the other as in Figure 6 below. It attempts to retain the insights of both paradigms while avoiding their pitfalls (Gemma 2019). CR was heavily shaped by the work of Roy Bhaskar, Andrew Sayer, and many other scholars (Danermark et al. 2002). Generally, Bhaskar was concerned with experimental science as a doorway into the way humans think about science. His fundamental idea was that if social scientists could understand why hard science succeeded, they may be able to comprehend how social research should progress.

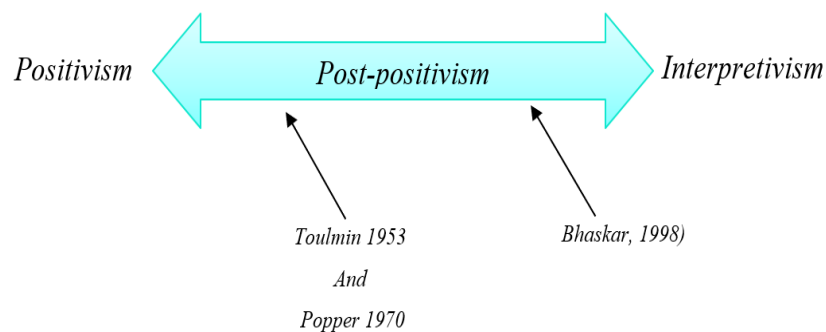


Figure 6. The post-positivist position in knowledge spectrum (Gemma 2019).

Some post-positivists are more inclined to positivism principles (e.g., Stephen Toulmin and Karl Popper) whereas others adopt a more balanced stance, according to the research problems and aims (Bhaskar 1989). Post-positivists who lean toward the positivist side on the knowledge spectrum may prioritise empirical studies following quantitative methods, while those who tend to the interpretivism side may favour qualitative or mixed methodology approaches.

Experimental research alone cannot provide a clear explanation of social phenomena (Bhaskar 1989; Collier 1994). Positivists believe they can follow natural science's epistemological and methodical guidance to study the social world. However, unlike the

social world, the natural world is made up of objects and forces that can be mathematically described (Danermark et al. 2002). The social realm, on the other hand, clearly possesses certain features. It is a combination of diverse elements such as behaviours, economics, and practices. All these contribute to the social world being more heterogeneous, contingent, and complicated than anything else in the natural world (Bhaskar 1989). Therefore, CR has advocated for shifting the focus from epistemology (what can be known) to ontology (what is the nature of reality). Positivism often conflates these two concepts, which Bhaskar regards as the epistemic fallacy (Bhaskar 2013).

### 3.3.1. CR as a meta-theory

Philosophical research paradigms shape basic assumptions to inform and guide meta-theories (Kuhn 1970). The assumptions that guide and orient theorising about a specific reality are known as meta-theory (Lawler and Ford 1993). CR is an example of a meta-theory. It is a term used to describe the philosophical stance, in which the main concern is to offer a philosophically grounded explanation of science (natural, social), which in turn, informs empirical research (Rutzou 2016).

#### 3.3.1.1. Ontology

Ontological realism—an enquiry into the nature of things—lies at the heart of CR (Sayer 2000). According to CR ontology, much reality exists and acts irrespective of our consciousness or understanding of it (Bhaskar (1979). Sociologists have preconceived notions regarding the nature of sequence, practises, people, and causal structures. These ideas cannot be reduced to empirical evidence, and they are frequently assumed while developing theories. Many of the world's phenomena may not be quantifiable, and may be difficult to articulate in language, numerals, models, or experimental investigation. These, according to Bhaskar (1979), can only be reconstructed by realist deductions: arguments that proceed from a social occurrence to theories that can explain them. To accomplish this, we need a toolbox full of a 'set of concepts', these must be suitable and responsive to the social world's unique characteristics. CR focuses on determining the ontological properties of the real world: the realities which generated the phenomena that were identified and examined. In this research it refers to understanding the realities of the UCB collection rate.

A fundamental ontological assumption of CR is that the world is complex and layered, and what can be seen is the result of a multiplicity of mechanisms (Lawson 1999). Thus, the world is characterised by Bhaskar (1979), as an open system, in direct opposition to the manipulated closed system of scientific realist methods. Scientific realist research requires a

manipulation of the system to isolate distinct variables which can be tested. However, Bhaskar (1979) emphasised that the social environment is always open, depriving social sciences of a predictive test for the development of new and current theories. This assumption underpins the researcher's approach and allows for abstraction to be the purpose of each stage of analysis (see the section on analysis for elaboration on abstraction). As the researcher's principal objective is to see the connections between structures and their interactions to reveal mechanisms, the open system perspective of the CR ontology allows for links to be made and generative powers to be ascertained. Thus, leading to contextualised and accurate deductions for the study context. This is consistent with the study's aim, as it may provide insight into the causal mechanisms that have resulted in the decline in UCBD and UCBC rates, and then reverse the effects of these mechanisms.

### 3.3.1.2. Epistemology

Ontological realists believe that social reality exists relatively independent of our inquiries and efforts to understand its nature (Bhaskar 1979). Thus, our understanding of these realities is constantly placed in historical, social, and cultural contexts. Knowledge is articulated from a variety of perspectives and concerns, and it is modified by our actions (Collier 1994; Danermark et al. 2002). In other words, what we know depends on the context in which it occurred. In the context of this research, knowledge about the reasons for the UCB collection rate declining can be understood from the perspectives of those involved in the programme itself. However, this knowledge about the UCB collection rate changes depends on the actions of those involved in the programme. The understanding of the UCB programme that is developed in this research is temporally bound to the contextual conditions in which data collection occurred.

According to CR this is not something that can be ignored, and a type of epistemic relativism should be adopted (Bhaskar 2009). Realists make no claim to having exclusive access to reality and do not dismiss other people's interpretations of the real-world. The world can only be understood through specific, historical descriptions (Bhaskar 2013). In other words, although realists believe in the existence of reality, neither reality nor rationality exist in isolation from their historical context (Sayer 2000). Therefore, all our images and viewpoints are limited in some way.

Science is fallible and empirical knowledge is shaped through conceptual frameworks that are not distinct ways of interpreting observed events (Danermark et al. 2002). In most cases breadth of scope is sacrificed for depth of understanding and CR epistemology aims to avoid

doing this. The fallibility of philosophical paradigms such as scientific realism, Bhaskar (1978) states, is that viewing phenomena within a closed system often simplifies the observed phenomena and reduces it to a series of linear events. In turn, this also reduces ontology to epistemology, i.e., reduces being to our knowledge of being (Danermark et al. 2002).

CR stresses the importance of distinguishing between ontological and epistemological assumptions. Understanding that there are entities outside our scope of awareness allows not only for the development of knowledge, but also accuracy due to the context-bound nature of the epistemological approaches. Bhaskar (1979) argues that due to human limitations all knowledge of the world is fallible, and whole truths may not be known but CR aids researchers to get as close to the truth as possible.

Epistemologically neither interpretivism nor statistical modelling are completely refuted by CR. Rather, these approaches are both utilised (Danermark et al. 2002). The goal in CR is to conduct a chronological investigation into artefacts, culture, social structures, people and the factors that influence human behaviour and interaction (Rutzou 2016). CR approaches causation critically, it uses observable events and facts encountered in society as a launch pad to understand the complex stratified reality and the root causes which generate those observed patterns and facts (Sayer 2000). To do this causality should not be reduced to a series of constant conjunctions, where event Y always comes after event Z. However, it is necessary to conduct a deep and rigorous account of causation, structures, and processes that can explain the reality with which we are concerned.

In this research, the epistemic goal of the study is to explore the causality of the fall in the UCB collection. In order to understand this, it was necessary to rigorously explore the perspectives and experiences of those individuals who were part of the UCB programme. It would have been insufficient to take their perspectives and experiences at face value in order to answer the research question. Instead, in line with the CR epistemology, knowledge about the cause of the fall in UCB collection required a process of abstraction from the perspectives and experiences that had been collected as data in this study. Through understanding the patterns that emerged from the data and the structures and mechanisms within the UCB programme, the causality of the UCB collection was revealed.

### 3.3.1.3. Stratification

The stratification of reality is both an ontological comment and an epistemological approach to understand the nature of reality or being (Collier 1994). The assumption that reality is stratified is a defining characteristic of CR. Stratification denotes that reality is stratified into

three layers, the empirical, actual and real domains of reality as in Figure 7 (Bhaskar 1978). Ontology and epistemology were both described earlier as separate entities, however, in the stratification of reality, CR states that epistemological questions lead to ontological revelations, thus they occur together.

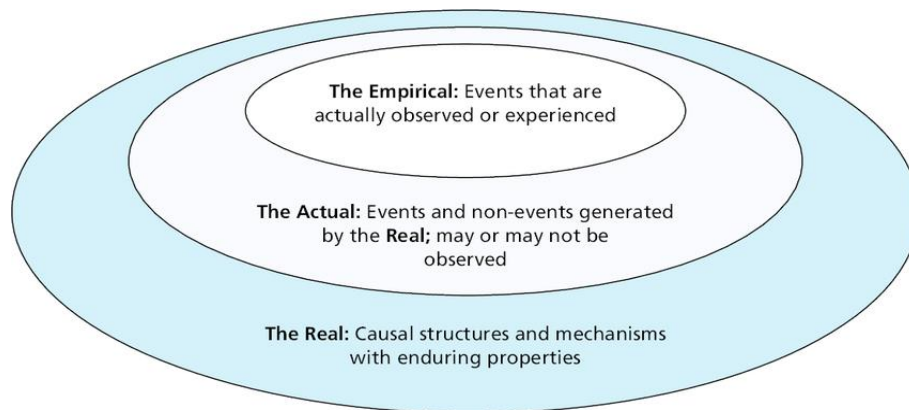


Figure 7. CR stratified ontology (Bhaskar 1978).

With reference to the above figure, reality in CR is understood as having 3 layers: the empirical, the actual and the real. The empirical layer of reality is where events can be seen through observation or experience (Kontos and Poland 2009; Wand et al. 2010). In this research this will refer to the events that have occurred, from the perspective of the participants of the study. The actual is where structures and their interactions reside, some of the entities of the actual layer of reality can be observed, while some remain hidden. This would refer to the many seen and unseen events, relationships, social, cultural, political structures, and other elements of the UCB programme that may impact on and are influenced by those who are part of the programme. The real layer of reality is likely to be the most vital element of stratified reality, where the mechanisms lie. The real contains the deep-rooted structures and their ability to generate events and mechanisms, which are entirely hidden (Outhwaite 1987; Sayer 2000). Unearthing these mechanisms and deciphering their generative powers pulls the focus from the empirical event to the causal root of events and experiences (Collier 1994). In this research, understanding the real is the aim of the study as it is concerned with the causes of the decline in UCB collection rate. Table 8 below shows the elements and where they can be found in the layers of reality.

Table 8. Domains of real, actual, and empirical (Bhaskar 1978, in Collier 1994).

	Domain of real	Domain actual	Domain of empirical
Generative mechanisms and structures of nature	✓		
Events and facts	✓	✓	
Experiences of sensemaking	✓	✓	✓

Based on Bhaskar’s theory, the stratification at the real, actual, and empirical domains is vital to CR due to the social world being an open system, rather than the closed system of the natural world. In this closed system, the natural world allows for the possibility of experimental conclusions (Williams 2005). Due to the nature of the social world, the open systems cannot be predicted through direct causation because of the multiplicity of relations occurring between layers of stratified ontology and between structures, agents, and culture (these terms are defined further in this chapter) (Downward et al. 2002). A major human characteristic is that change, and renewal are constant (Danermark et al. 2002). The health system shows that change can positively influence practice (Grol and Wensing, 2004). The combination of human actions and our aptitude to develop as we learn, allows for a continual modification of systems. This is a major principle in CR, to continually grow for the goal of human freedom (Bhaskar 2013).

CR aims to make reality evident by revealing the mechanisms or structures that generate observable phenomena or events. Porter (2001) offers an example of how philosophers would view AIDS from different theoretical standpoints. The researcher viewing the phenomena from a positivist stance would focus on unearthing the cause of AIDS and its transmission. While the interpretivist attempts to explore the experiences of individuals affected by AIDS from different aspects (i.e., social, occupational, family). CR researchers, however, aim to methodically search beneath the observable events, exposing principles, beliefs, and relationships to uncover the roots and contexts that influenced the study phenomena, thereby uncovering the unobservable mechanisms. In a similar way, the stratified reality of CR will be the driving force in uncovering a few key elements in the UCB programme that inhibit or aid UCBD and UCBC. This extensive analysis, enabled by CR, provided a platform for answering the why question by delving into the genuine underpinning causal structures that produced this study phenomenon, whilst taking the



context into account. Therefore, CR was the appropriate approach for answering this study question.

#### 3.3.1.4. Structure and agency

CR contends that agency and structure have separate traits and capacities that cannot be combined. The social world is automatically monitored by humans who exercise power at the individual or group level, adjusting relatively durable yet emergent causal mechanisms. To understand agents' decisions, it is necessary to consider the structure's limitations and its empowering features or qualities. According to Archer (1995), any social event can be investigated by understanding how agents, structures, and cultural systems interact at different times. Every system possesses a certain level of autonomy and emerging power, which can be a limitation and/or opportunity for different systems. CR explores structures and agencies independently with an emphasis on their inter-correlation as well as the circumstances and potential they create. According to Archer (1995), keeping structures and agency distinct for the purposes of analysis is necessary if we are to create meaningful social theories.

Human actions produce and or sustain social and cultural structures, which are pre-existing at any given time, giving them autonomy as viable areas of research. Social structures are long-lasting (but not indestructible) aspects of the world that frequently precede and follow our individual lives. Human agency, on the other hand, can perpetuate structures or modify them over time (Bhaskar 1979; Archer 2010).

#### 3.3.2. Critical Realism: As an analytical method

This section will link CR theory to analytical methods. To begin, the three domains of CR – empirical, actual, and real – offered an overall conceptual frame through which the social world may be accessed. The explicit descriptions of these domains provided comprehensive explanation of how CR as a philosophy informs research design. Specifically, the iterative process of moving from theoretical abstraction to practical experience. Therefore, CR analysis heavily relies on the iterative abstraction process, which underpins the whole analytic process (Ollman 1998; Sayer 1998; Danermark et al. 2002). Abstraction is the way through which CR studies achieve the depth demanded by social science. Although, it is not a ready-made or simple technique to use since it requires extensive thought (Pratt 1995).

In CR analysis, there are two major stages: structural and causal analysis, these are addressed via abduction and retroduction, respectively. I begin by giving a thorough overview of

abstraction as an analytical process that underpins the whole analytical process (Ollman 1998). The three chosen steps in CR analysis are then presented, mainly based on the guidelines presented by Wynn and Williams (2012). The first describes observed events and experiences (demi-regularities). The second step is abduction (explicating structures), this determines the nature of objects and their relationships in the phenomena being studied. The third step is retroduction which elaborates on the way inherent power or tendencies of structures interact to bring about the explicated events (Wynn and Williams 2012).

### 3.3.2.1. Abstraction

CR is a method that combines theoretical abstraction with empirical observation (Outhwaite 1987). Heading back to CR stratified ontology, realists assert that the generative mechanisms, which cause events in the world, can be revealed at the deepest level of the 'real'. (Danermark et al. 2002). The primary goal of theoretical abstraction is to separate the 'causal mechanisms' and 'structures' that take place in the 'real' domain (Yeung 1997). The abstractive approach is central to two key stages of analysis that are unique to CR research, these are abduction and retroduction. Both (abduction-retroduction) are examples of 'as if' reasoning. A shift in one's perception of a phenomenon to a completely different perception of the same structure, object, mechanism, or circumstance causing the observed phenomenon (Lawson 2003).

Abstraction is necessary for conceptualising the research object and making research effective in explaining social circumstances (Sayer 2000; Danermark et al. 2002). Abstraction helps us to understand the world's distinctions: by isolating entities and categorising their properties and connections. To be useful for a given goal, it should 'abstract' from particular circumstances (Sayer 1992). In other words, research work should be based in the concrete (Sayer 1992; Danermark et al. 2002). The reason for this is that research is abstracted from the various elements of the social world which include 'concrete' entities, such as individuals, organisations, and activities. A two-step procedure is used to achieve this: concrete to abstract, then abstract to concrete (Sayer 2000).

Although concrete is a combination of various abstract components and required relationships, empirical study can define its shape and whether it is observable (Sayer 2000). To put it another way, empirical research alone does not always explain concrete phenomena; empirical research must be supplemented with theoretical and rational abstraction (Outhwaite 1987). A tendency to cling to suggestive thoughts and thoughts is

formed by intuition, observation, and sensitivity or preparation, and the ability to transit between the abstract and the tangible necessitates creativity (Layder 1998).

It is worth noting that in CR research, empirical facts are emphasised as significant (Wynn and Williams 2012). It is vital to base research on real-world data, according to Wynn and Williams (2012), so that abstractions do not arise in a vacuum. Sayer also warns against excessive theoretical abstraction in the absence of factual evidence of the concrete, as it can result in misleading studies which favour unproven theories above reality (Sayer 1992). This is referred to as empirically anchoring research by Layder (1998), in which the facts provide a categorical, sufficient access point into the phenomena. The importance of empirical research grounding, not only at the start but throughout the abstract concrete process, is crucial to the study described in this thesis.

### 3.3.2.2. Demi-Regularities

The CR views the world as a complex entity of open systems, therefore causal laws are not determined (Brown et al. 2002; Danermark et al. 2002). As such, CR does not look for laws, but rather looks for tendencies and trends (Danermark et al. 2002). On the empirical layer of CR ontology, trends and patterns can be observed, these observations give us notions on the causal events to account for the phenomena. However, in CR, these trends are not the causation of events and experiences but can provide insight into the underpinning structures through abductive analysis and causal powers of mechanisms in retroduction. Demi-regularities are defined as “an event that holds imperfectly over a restricted region of space-time” (Hartwig 2007, p.89). Demi-regularities are a useful tool in analysis, grouping broken trends together to provide a basis for the abductive step of analysis. The term ‘broken patterns’ refers to the fallibility of demi-regularity, the causal effects cannot be discernibly identified rather a prediction can occur (Lawson 1997). It is likely that ‘Y’ occurs as a result of ‘X’, but it is not an absolute prediction. Predictions of ‘Y’ occurring as a result of ‘X’ is not possible in this open system, though CR does acknowledge that social meanings, thoughts and decisions can have consequential impacts on the world.

In this study, demi-regularities were the term used to describe the empirical trends and patterns seen and recorded in interviews in the first stage of analysis (see Findings: Chapter four). These patterns were inductively deduced from collected data. From there, the inner structures can be realised thus giving rise to generative and dormant mechanisms.

### 3.3.2.3. Abduction and Retroduction

According to Habermas (1972), abduction is a type of inference that expands our understanding and motivates the research workflow. In other words, abduction is a process of re-contextualisation, where the researcher analyses and explains a phenomenon in a new context. Its purpose is to remove data from the empirical layer of reality and move it to new contexts of preconceived theories (Wynn and Williams 2012). By viewing the empirical findings through a different, theoretical lens, the observed phenomenon is re-described to develop causality (Danermark et al. 2002). For example, Giddens (1991) re-contextualised the term anorexia as a symptom of what he called 'reflexive identity', and later became a feature of postmodernity. Similarly, a physician employs 'abductive logic' to interpret patient-defined manifestations. Physicians can derive a reasonable understanding of the underlying cause of a disease by referring to rules or trends that they believe are plausible.

Abduction can be used as a tool to remove unnecessary information from empirical events, allow movement away from the minutiae of individuals' experiences and to reframe the events within concepts, ideas and social structures. Thus, we proceed from the surface toward reality's depths, from the empirical realm findings (in Chapter four) to the domain of structures and mechanisms in (Chapter five). This occurs when we interpret and re-frame the original thoughts regarding a phenomenon in a new context. So, the knowledge obtained through established theory, by building on said theories, develops the theory itself by adding novel situations such as a UCBC programme in KSA. This research is delving into novel territory as public UCB programmes in KSA are an emerging phenomenon. Therefore, applying existing theories will conceptually re-describe data and will add new contexts to the chosen theory. It is necessary in CR analysis to move beyond empirical data to the underlying reality of causal mechanisms. Abduction and retroduction are the main methods used to achieve this transition. In order to clarify the chain of causality that results in recurrent patterns in events, this stage entails re-describing the observed phenomena in terms of pertinent theories.

During retroduction, several interpretations are suggested, each of which details a causation mechanism, these are embedded in social structures which should be true for the empirical events to occur (Wynn and Williams 2012). The process of retroduction is creative and requires extensive thought and reconsideration to propose mechanisms. Proposing mechanisms requires some conjecture to bring forth reasons for the empirical events, multiple scenarios are thought of and the most likely of these leads to a possible mechanism.

As mechanisms are rarely seen or observed directly, the mechanism retroductively provides a logical argument to explain how empirical events have come to occur. This is done by bringing forth likely structures and their power to generate the event within the context of the study (Sayer 2000).

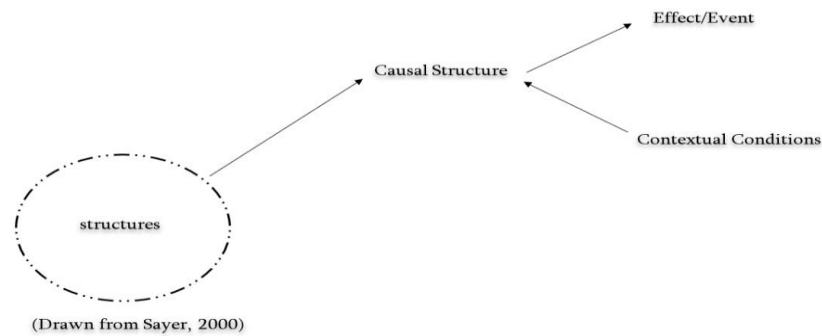


Figure 8. Structure of a mechanism (Sayer, 2000).

Figure 8 represents the mechanism and its components starting from the structures on the left and resulting in the effect or event on the right, under specific contextual conditions. It is important to note that the terms 'causal structure' and mechanism are not interchangeable. The term mechanism refers to the way in which a structured entity works or operates. Given that this is an open social system, the purpose of a mechanism is to determine what factors or structures within this open system are causing or generating the observed event.

In the above figure, an entity's structure includes mechanisms that generate occurrences directed from left to right. Other entities on the figure's right side possess mechanisms that act as contextual conditions and affect the mechanisms of the entities on the left side. Essentially, this involves granting entities with powers independently, without reference to any particular sequence of occurrences: not just when C gives rise to E, but even when C does not drive to E. ...etc. as we're dealing with open systems (Sayer 1992). To propose mechanisms (once structures have been explicated), (Danermark et al. 2002) gave CR analysts the following questions, what causes the empirical event? or what features should the events possess in order to exist in the way it does? To bring forth the possible mechanisms, the most logically feasible explanation of the empirical events (considering contextual conditions) is identified.

Retroduction is the process of bringing about contextual conditions, mechanism, and the powers of inner structures accounting for empirical events (Bhaskar 1978). Contextual conditions are given by (Sayer 2000) as the wider societal and cultural contexts that

individuals are raised in and exposed to in daily decision-making. During the retroduction step in CR analysis, deeper explanations are given to understand the empirical events in findings (demi-regularities). The contextual conditions and their influence on the individuals in the study are explicated during retroduction (Danermark et al. 2002). Contextual conditions can aid a further understanding of the importance of context on the structures of the UCB programme.

Retroduction enables emergent mechanisms and structures to be uncovered. Mechanisms can be latent and remain covered whilst other mechanisms can reveal themselves; these are defined as possessing emergent powers (Danermark et al. 2002). Emergent mechanisms are those that possess causal power and are responsible for the events that are observed. For a CR analysis to fully grasp the underlying causal processes that give rise to perceived patterns or regularities in social events and structures, emergent mechanisms must be understood and identified. Researchers can learn more about the complexity and generative mechanisms that contribute to the social phenomena they are studying by recognising the emergent features and mechanisms.

During the data analysis process many of the structures revealed were in relation to individuals' personal beliefs and actions, despite efforts to turn the focus away from intricacies observed in the findings. However, retroduction can produce results regarding individuals' beliefs and the reasons for their actions (Wynn and Williams 2012). To understand the barriers and facilitators of the UCB programme, an understanding of the reasons behind an individual's actions is vital. However, in order to understand an individual's beliefs is not to validate their thought processes, individuals are likely to be unaware of the intransitive world or may misunderstand their beliefs (Mingers 2006). However, an understanding of personal views and beliefs has been useful in contextualising participants' actions. In this study, abduction gave rise to the structures that exist within the programme and their interactions. In the process of retroduction a combination of connected structures will be extracted from the data, thus providing several possible mechanisms to answer the research question in Chapter five.

### 3.3.3. CR Critiques

The principles of CR are appealing for researchers who seek to develop an understanding of the world. However, some researchers claim that the philosophical standpoint adopted by CR is not sufficiently rigorous for theories to be developed based on its findings. Wainwright (1997) advises that CR should follow a more conservative principle to ensure that speculation

and plausibility are clearly differentiated. Within this research, the decline in UCBD and UCBC in KSA is a fact as presented in the literature review, and to explore the reasons behind this decline, a combination of data was collected. This research is transparent in how the findings are developed, using direct quotations and observational and document data, and through a clear description of the analytical process. Therefore, the findings of this research are not merely speculations of possible causes of the decline in UCBD and UCBC; they are plausible because they are supported by empirical data.

In addition, the accusation that CR is not rigorous may be too harsh. There are several stages of analysis where mechanisms are examined empirically, tested and refined through the process of abstraction, abduction and retroduction as explained in the previous section. This rigorous method of extracting mechanisms does allow for trustworthy conclusions to be drawn as argued by Danermark (2002), Sayer (2002) and Bhaskar (1989).

Some researchers argue that in CR, the real world exists beyond human comprehension, thus knowledge developed about the world is fallible (Cruickshank 2011). However, while this epistemic fallacy is the skeptical position taken on knowledge development in CR, CR researchers also believe that their theories about the world are reliable, owing to their extensive analytical method, until there is existing evidence to prove otherwise. In other words, in CR, theories developed are reliable at the point of development and are similarly subjected to the epistemic fallacy. This epistemic fallacy is accepted within this research. Data gathered in this study is contextualised within KSA and explores the phenomenon at the point of data collection. This study does not make an attempt to generalise its findings to other UCBBs locally or overseas, and also accepts that the findings are reliable insofar as they are supported by the data, existing theories and the abduction and retroduction process. Further research in this area may thus differ in their findings to this research.

Terminology has been a contentious point for researchers critiquing CR, as some vague explanations of defining pillars of the paradigm can lead to errors. Some researchers argue that Bhaskar (1989) has been unclear with some defining terms: structure, powers, tendencies, and mechanisms (Mingers 2011). In addition, researchers have discussed CR in various ways, as a methodology, dogma, or an epistemology (Yeung 1997). This lack of clarity leads to confusion for researchers wishing to apply the paradigm to their own research. Yet, Bhaskar's (1989) philosophy is to coordinate the paradigm within the realms of public health and programme evaluation (Wand et al. 2010), and it resonates with the aims of this study. However, as the researcher, I did find some difficulty with the practical application of the

paradigm due to the ambiguity around terminologies. To overcome this challenge, I attended several workshops and discussed the issue with my supervisors and researchers who had experience in applying CR as a research paradigm. This provided me with clarification on concepts that I found challenging.

The route of selecting the CR paradigm has now been fully explored, justified, and clarified, other methodological theoretically applicable approaches will be outlined and discussed with regards to the context of this study.

### 3.3.4. Alternative methodological approaches

At this point it was necessary to highlight the possible research methodologies that were considered, but excluded for this study, and describe why a flexible, qualitative research design was selected.

#### 3.3.4.1. Ethnography

Ethnography was considered as an alternative methodological approach; it refers to an enquiry of social group or culture (Holloway and Todres 2010a). However, understanding culture is vastly complex (Whitehead 2004). Despite these complexities, the researcher felt that an approach on evaluating context required further consideration. It has been argued that ethnography can add to ideas raised in realist studies, and realist researchers do not confine themselves to the experiences of social groups (Robson 1993; Holloway and Todres 2010a). However, it focusses on the identification of causal mechanisms, which can bring forth varied outcomes (Kazi 2003). In addition, participant observations are imperative in ethnographic studies and this focus may have resulted in the neglect of causal mechanisms. The overarching goal of the study was to understand the social structures that affected the participant groups. Ethnographic methods were deemed unsuitable for this function. Thus, ethnography was inappropriate to use as a methodological framework for this study.

#### 3.3.4.2. Grounded Theory

Amongst the methodological approaches excluded was grounded theory. Grounded theory was developed on the basis of interactionism and can be closely aligned with the critical realist's ontological stance (Annells 1996). Grounded theory may have been appropriate for this study due to its data driven approach, however, there is a lack of focus on culture and social structures which were important considerations in this research (Holloway and Todres 2010b). The researcher in this study prioritised the use of a methodology that highlighted factors which could lead to barriers, and facilitators of UCBD and UCBC. Furthermore, the



interactionism element of grounded theory did not resonate with the main aims of the researcher, the social structures influencing the participants were deemed to be a higher priority. In literature, it was already well established that there were individual barriers to UCBD and UCBC. I wanted to focus on wider elements that affected “the whole” as opposed to individual elements influencing the UCBC rate.

## 3.4. Method

Following the selection of a philosophical paradigm, the next step was to choose a suitable research methodology to address the study problem. In this part of the chapter, the research aims and objectives will be established, and the chosen study design, method of data collection and analysis will be discussed.

This research aims to theorise an explanation for the potential barriers and facilitators, which contribute to the decline in UCBD and UCBC rate in KSA. This may provide recommendations to maintain the UCB infrastructure and to stabilise the UCBC rate to meet market demands.

### 3.4.1. Objectives

The objectives of this study are as follows, categorised as primary and secondary objectives.

#### 3.4.1.1. Primary objectives

1. To explore local barriers and facilitators to the collection of the UCB from healthcare professionals’ perspectives.
2. To explore local barriers and facilitators to the donation of the UCB from pregnant mothers’ perspectives.

#### 3.4.1.2. Secondary

To present tailored recommendations based on the analysis of empirical data and literature findings.

### 3.4.2. Research Design

The research design denotes the blueprint used by the researcher to combine the research components in a consistent and logical manner (Grover 2015). It ensures that the researcher employed the appropriate methodologies, data collection, analysis, and ethical consideration to conduct credible research work (Creswell 1998). It is driven by the researcher's underpinning philosophical stance, with the main purpose of addressing the research questions. A defective or weak study design may misinform the research question, rendering

the study results unreliable. In this study, although there is an official partnership programme between the public UCBB in KSA and PHMD to collect the UCB units, it seems that the collection rate has reduced in recent years. This is signified by the small ratio of collected units to the number of annual deliveries (nearly 1000 collected UCB vs. 8000 annual births in 2010) and the decreased collection rate over time (318 units vs. 8000 annual births in 2018) (Chapter one, Figure 1, p. 3).

Either quantitative or mixed-method research approaches can be utilised in this study context. Explanatory in-depth investigation necessitates the use of a qualitative study to understand the possible barriers and enablers of UCBD and UCBC within the study setting. Due to the innovation of UCBC in KSA it was necessary to develop a deep understanding of the phenomena at hand. Often, qualitative research can be an antecedent to quantitative methods, where experience of a phenomena is established in literature before a hypothesised, quantitative study can be of use (Dixon-Woods et al. 2001). There is a notable dearth of studies that explore UCBC in KSA and this study aimed to fill that gap. The few studies which were found in the literature concerned quantitative methods that were necessary for the technical, medical field of stem cell therapies in relation to UCB, rather than UCBC. In addition, the study problem involved several participant groups: parents, UCB teams, midwives, antenatal teams, and policymakers. Understanding each distinct group's concerns and experiences required qualitative methods, as quantitative analysis would not have adequately described the nuances presented by each group. Qualitative research method was therefore the appropriate choice and within this an investigative, qualitative research design was used. This entailed collecting data from numerous sources (such as interviews and observation). This study ultimately aimed to produce a theory based on the mechanisms that accounted for the studied phenomenon. According to Bogdan and Biklen (2003), meaning is central to the qualitative method, thus I concentrated on participant views. Data could be analysed retroductively to identify the underlying structures and conclusions then drawn regarding the research question in accordance with the chosen philosophical paradigm.

#### 3.4.2.1. Research methodology

Methodology in research refers to the overarching strategy that is used by the researcher to address the study questions (Remenyi et al. 2003). Selecting a research methodology depends on the manner of the research question, the researcher's effect on studied phenomena, and how much attention is paid to current or past events by the researcher (Yin

2003). The researcher's philosophical stance, time allotted for the study, available resources and knowledge on the topic area are all essential factors that should be considered when selecting the research methodology (Saunders et al. 2009). Ethnography, grounded theory, and general qualitative research were options.

#### 3.4.2.2. CR as a methodology

CR is a philosophical methodology, it is a way of exploring the social world and examining empirical evidence. However, to support the collection of this empirical evidence CR researchers use a variety of methodologies and research designs, such as case studies, action research, intensive realist literature evaluations etc. (Vincent and O' Mahoney 2018). Adopting a pluralist approach to methodology, CR researchers advocate for the use of a broad range of data collection methods (Vincent and O' Mahoney 2018).

Some CR researchers consider CR to be a methodology by its own right, with its key foci on abduction and retroduction (Fletcher 2017; Vincent and O' Mahoney 2018). Being a meta-theory, CR has philosophical groundings in its ontology and epistemology in order to defend itself as a methodology (Vincent and O' Mahoney 2018). On the quest to unravel the social world, CR prioritises approaches to data collection that allow the researcher to explore the stratified reality and the generative mechanisms of the studied phenomenon. The focus thus shifts from how data is being collected to how the data is being understood.

For example, in Fletcher (2017), CR was applied as a philosophical and methodological framework. As a methodological framework, Fletcher (2017) considered two ways in which empirical events were observed: by using census data on Canadian agriculture and using semi-structured interviews. A rigorous CR-informed abduction and retroduction of the data was conducted as a means of analysing the data through the CR lens. In other examples, Robinson (2022) and Williams (2018) employed a general cross-sectional qualitative methodology, they used interviews as the method of data collection and CR thematic analysis for data analysis.

This research study on the UCB programme in KSA follows the methodological perspective of Fletcher (2017). CR, being the theoretical lens and methodological backbone for this research, enabled the in-depth exploration of the causes of the decline in the UCB collection rate. Fletcher's (2017) work paved the way for CR researchers to understand how the ontological and epistemological perspective of CR could provide methodological directions as to how data should be collected and understood.

However, the pluralist approach to data collection required me to seek further direction on the method of data collection. This research is chiefly focussed on one setting (a public UCB bank in KSA) and the perspectives of the agents within the programme (midwives, UCB nurses, policymakers). For this reason, I looked at case study methodology for guidance on how the data should be collected. However, case study methodology was not applied explicitly because of the way data is analysed in case study research. Because of the influence of CR on this research, the focus on abduction and retroduction in CR superseded the analytical methods applied in case studies such as cross case analysis. Therefore, whilst influences of case study methodology can be observed in the design of this study, this study asserts that CR is the methodology of choice. This approach to CR research is permitted by its pluralistic methodological perspective. A qualitative approach was used to collect data in this study, and this is explained in the next section.

#### 3.4.2.3. Qualitative Research Study

Research design in qualitative studies should be a reflexive process that operates through every stage of a project. The activities of collecting and analysing data, developing, and modifying theory, and identifying and dealing with validity threats should happen simultaneously and each should influence the other. The traditional typological or linear approaches to research design, which provide a prescriptive guide for planning and conducting a study in a particular order, may not be suitable for qualitative research as it requires a broader and less restrictive concept of design.

Maxwell (2012) presented an interactive model of research design that consisted of five components: goals, conceptual framework, research questions, methods, and validity. The goals component addresses the reasons for conducting the study, the issues to be clarified, and the practices and policies to be influenced. According to Ravitch and Riggan (2016), the conceptual framework component focuses on the theories, beliefs, and prior research findings that will guide the research. Additionally, it encompasses the examination of existing literature, preliminary studies, and personal experiences to enhance the understanding of the people or issues being studied. The research questions component identifies the specific things to be learned or understood through the study and the relationships between the research questions. The methods component outlines the approaches and techniques to be used in collecting and analysing data, and how these constitute an integrated strategy (Maxwell 2012). The validity component addresses the potential alternative interpretations

and validity threats to the results and conclusions, and how these will be dealt with (Seale 1999; Maxwell 2012).

This model of research design is intended to help researchers understand the structure of their study and to plan and carry it out. It treats research design as a real entity, not simply an abstraction or plan. The author also acknowledges that ethics is an important consideration in qualitative research, but it is not identified as a separate component in the model.

The goal of qualitative research is to examine and comprehend the wide-ranging complexities and significance of human experiences and social phenomena (Maxwell 2009). The methodology is used to develop an in-depth understanding of the study issue by collecting data in the form of observations, interviews, documents, and artefacts. The main aim of qualitative research is to explore the individualised meanings, viewpoints, and perceptions of individuals or groups in order to understand how reality is socially created (Creswell 1998). It provides a nuanced and comprehensive understanding of the events being studied, going beyond statistical analysis and quantitative measures. In this study, there were many areas of complexity that required careful thought and analysis. The partnership between a tertiary and a public maternity hospital, two departments with differing aims and objectives and five groups within these departments with their own contexts and behaviours. Deciphering the causal relationships between structures, people and institutions required a flexible approach.

Further, the flexibility of general qualitative study design is particularly well suited for examining subjective experiences in-depth. A general qualitative study provides the freedom to investigate and unearth the rich and nuanced parts of human experiences when the research objective is to dive into the lived experiences, emotions, or motives of participants (Seale 1999). In this study participants were asked about their experiences of collecting UCB. Differing viewpoints were expressed in the responses, these required a flexible research methodology to decipher and decode. Additionally, the flexibility of the research method was well suited to adapt to the subjective nature of semi-structured interviews. This in turn allowed for increased engagement and trust from participants, thus increasing the veracity of responses (Creswell 2013).

Qualitative research studies are crucial in rapidly growing fields, they expand our understanding of a phenomena, particularly in a scantily researched field (Tenny et al. 2017). In KSA, UCB collection and public CBB is still in its first phase. As the current study context is relatively uncharted, it is necessary to utilise a research method that is not constrained by

established ideas or presumptions. Researchers collected information from participants who were directly involved in the emergent phenomena, giving them valuable and contextual insights that help to develop an understanding of the emerging phenomena. For the reasons highlighted above general qualitative research design was utilised in the study.

### 3.4.3. Research process

In the previous section of this chapter, the suitability of various methodologies was discussed regarding their suitability to fulfil the study aims and research question. The approach to participant recruitment, design of interview questions, data collection, and analysis will be outlined below.

#### 3.4.3.1. Recruitment and sampling procedure

Once ethical approvals had been granted by the relevant organisations (see Appendix B), I contacted the manager at the PHMD to request access to the hospital's directory and got in touch with the appropriate departments. Doctors and nurses from the prenatal, antenatal and delivery wards were contacted, and permission was obtained from all department heads to contact their staff.

When permissions were granted, I was able to conduct presentations for staff about the research. During the presentations, managers reassured staff that participation in the study was optional and that refusing to do so would have no effect on them. Verbal consent from interested staff members was then obtained in those meetings.

Following the approval of all staff, administrators, ethics boards and relevant individuals, I ensured that staff at the wards pertaining to the study were familiar with me. I would be there for assurances, to provide extra communication verbally, or in the form of information sheets. I also tried to gain the employees' trust so that they would act normally and feel comfortable speaking candidly during interviews or observations. I sought the permission of the head nurse to meet the staff and have a brief discussion with them after the routine shift handover. This took place on several occasions to cover all the work shifts and to ensure that everyone was familiar with the study process. At the beginning of every meeting, refreshments were served, followed by a ten-minute talk about the research aim, data confidentiality, participants' rights, and study processes for data collection. Acquisition of informed written and verbal consent occurred, and information sheets were provided to participants (Appendix C).

The antenatal nurses were the initial point of contact for pregnant mothers. They introduced me to the pregnant mothers, who met the study inclusion criteria, every morning in the pre-assessment room (vital signs and weight room). The nurse explained the purpose of the study to the mothers. If the mother agreed I would then explain the study in detail and provide the mothers with a PIS. The mothers were given time to read the information sheet and decide whether they would like to participate. The mothers were then seen at their next appointment, generally a two-week period (as they were typically in their third trimester) and at this point would give their decision. The participants received a PIS that included the contact details of the student researcher to answer any further enquiries during or after data collection. The PIS also included the contact details and website of the Saudi public UCBB for stem cells donation in case participants had further enquiries. This ensured that all participants had sufficient time to make an informed decision. If the mother agreed to take part her details were noted, the antenatal nurse provided me with the mother's next appointment date.

As the UCBC process was complex and it was considered important to hear the views of all parties participate (donor mothers, healthcare professionals and policymakers) a total of 37 interviews were conducted across two sites: UCBBH and PHMD. The UCBBH is the tertiary hospital that houses the UCBB. The UCB nurses and policymakers were recruited from this site using convenience sampling as there was only one public UCBB in KSA. The PHMD is a separate hospital, and this was the location for UCBC to take place. Within this department, the antenatal department and midwives were recruited. Convenience sampling was also used for the antenatal department as PHMD is the sole hospital with which the UCBB has an existing partnership. However, as midwives at the PHMD collected UCB units voluntarily, purposive sampling was more appropriate. It enabled me to sample a selection of midwives some of whom collected regularly and others who did not. This provided me with an opportunity to understand the barriers and facilitators influencing the collection of UCB by these midwives.

Appendix D shows the number of UCB units collected by midwives throughout the data collection period. Table 9 below shows the number of participants approached for the recruitment of this study and the number that consented.

Table 9. Study's participant groups (the study units of analysis).

<i>Study participants</i>		<i>Approached</i>	<i>Consented</i>	<i>Interviewed</i>
<i>Site one (UCBBH)</i>				
<i>UCB nurses</i>		5	5	
<i>Policymaker</i>		4	3	8
<i>Site two (PHMD)</i>				
<i>Midwives</i>		36	6	29
<i>Antenatal team</i>	<i>Antenatal nurses</i>	8	5	
	<i>Obstetricians</i>	49	5	
<i>Policymakers</i>		4	4	
<i>Pregnant mothers</i>		23	9	
<i>Total</i>		129	37	37

To ensure that interview data was collected appropriately, interviews commenced, these were recorded once verbal and written consent had been granted by participants. Some interviewees chose to talk exclusively in Arabic, while others alternated between Arabic and English. Therefore, recording the interviews was also beneficial to ensure the accuracy of translated transcripts from Arabic to English.

The number of midwives and obstetricians who consented to the research was quite low despite repeated invitations, encouragement from the head nurse and head of medical health department throughout the data collection period, visiting ward rounds and small incentives (Starbucks vouchers). There were also 15 midwives on maternity and annual leave during the period of data collection.

For the mothers, participation in the research was considered inconvenient as their male relatives were waiting for them outside after their appointment. To ease the recruitment, mothers were recruited during their Oral Glucose Tolerance Test where there is a waiting time of 3 hours. Mothers were still reluctant to take part in the research because mothers in the region served by the PHMD were more reserved culturally and were not comfortable



with speaking to people, they were not familiar with, such as the researcher. This was despite having antenatal nurses introduce the mothers to the research and researcher.

Fathers were not included in the research because the hospital, where this research was conducted, only allow the mother to enter the clinic unless there is an urgent medical need for the fathers to be involved i.e., complications, need for caesarean section. Additionally, there was a lack of space to accommodate both parents and myself for data collection in the hospital.

#### **3.4.3.1.1. Mothers' recruitment**

Antenatal nurses were the initial point of contact for mothers. The pregnant mothers when attending clinic first attended the pre-assessment room (vital signs and weight room).

The nurse provided mothers with a brief introduction and informed them of the purpose of the study. If the mother agreed, the nurse allowed me to give them full details of the study and they were handed a participant information sheet (PIS) as in Appendix C. The mother was given two weeks to read the information sheet so that she could make a decision on whether she wished to participate. The PIS included the contact details of the student researcher, the contact details and website of the Saudi public UCB bank for stem cell donation was also provided so that they could answer enquiries after data collection. This ensured that all participants had sufficient time and information to make an informed decision. If the mother agrees, I arrange a meeting with her on the day of her Glucose Tolerance Test (GTT). The mother could be interviewed and enrolled in the research while waiting for the GTT results, which takes around three hours. Written consent was collected prior to the interviews.

#### **3.4.3.1.2. Healthcare workers sampling and data collection**

Study setting A: The maternity hospital:

Once ethics approval had been granted by the Saudi ministry of health, the hospital manager forwarded a copy of the approval letter to the medical director and the nursing director. The nursing director arranged for me to meet the head nurses of the labour room and also the head nurse of the outpatient department. Each head nurse introduced me and outlined the study purpose to their staff members.

In the first week I familiarised myself with the study setting and staff in order to reduce any concerns they may have. I also provided four information sessions on the study details and myself for both the day and nightshift staff. All staff were given the opportunity to ask

questions. A private session was scheduled for those who were not able to attend the information sessions but were interested in taking part in the study.

The obstetricians were busy but were informed officially about the study by the medical director. I met many of them in the field, namely in the outpatient department (OPD) and labour ward, where I took the opportunity to introduce myself and the study. Some obstetricians gave me specific appointments for the interview while others were not able to do so due to their heavy workload. Therefore, I stayed on the ward for 12-hour shifts, varying between day and night shifts for three months, in order to catch opportunities to interview them.

Similar steps were taken with the policymakers (medical and nursing directors, (the two head nurses. All the healthcare midwives, obstetricians, antenatal nurses, and policymakers who met the study inclusion criteria were invited to take part in the study.

Study setting B: The public UCB bank in KSA:

The UCBB is placed in a tertiary semi-governmental independent hospital, for this reason a separate ethical approval letter issued from their own research centre was required. When the ethical approval letter (see Appendix B) had been obtained, the nursing research department directed me to contact the UCBB supervisor for an appointment. At this appointment, I introduced the study, provided her with the PIS and consent form and answered any questions she had. Written consent to take part was obtained and approval was granted to recruit UCB nurses for the study. UCB nurses were subsequently approached, and the PIS and consent forms were provided.

The UCB programme was started as a result of pressure from the haematology and oncology consultants, it was therefore essential to involve them in the study. Thus, I asked the oncology and haematology heads to invite their consultants to take part in the study, two responded. The PIS and consent forms were provided via email. Data collection took place in an unoccupied assessment room within the OPD department. Prior to starting the interview, the signed consent forms were collected and checked. Participants were reminded of their right to withdraw from the study and that the data collected would be confidential.

#### 3.4.4. Data Collection

CR adopts a holistic approach to data collection. Methodological decisions should be based on the nature of the study topic and the researcher's objectives (Sayer 2000). Critical realists assert that a range of data sources, theoretical approaches and analytical techniques are

required to enhance causal analysis. This is necessary to overcome the perceptual constraints of researchers (Wynn and Williams 2012). In this research, three different approaches to data collection were employed in this research: semi-structured interviews, field note observations, and documentation.

#### 3.4.4.1. Interviews

The interview is a primary source for first-hand information in qualitative research and is a reputable instrument for data collection (King and Horrocks (2010). Interviews can offer more detailed and thorough information than surveys (Shneiderman and Plaisant 2006). A small number of participants can provide the researcher with extensive data. Also, direct interaction with participants enables the researcher to keep a close eye on data quality and assess whether it appropriately answers study questions. This on-going interaction during interviews enables the researcher to make immediate adjustments if necessary.

The most common types of in-depth interviews are either unstructured or semi-structured (Morse 2012). The study nature and objectives are key elements in determining the most appropriate interview format. Unstructured interviews are recommended for long-term investigations because they enable participants to express themselves freely and without restriction (Corbin and Morse 2003). It is widely employed by ethnographers, who pioneered its applications by combining it with observation, records, and field notes.

In semi-structured interviews, participants are asked to respond to predetermined, but flexible and unrestricted interview questions. They are commonly used in the healthcare field of research. The interview often varies between 30 minutes up to an hour or more. Semi-structured interviews can be helpful in the development of informative rich narratives, while keeping the interview focus on the intended outcome (DiCicco-Bloom and Crabtree 2006; Zachariadis et al. 2013). This research employed semi-structured interviews due to their flexibility. This method allows a mix of open and close-ended questions, enabling researchers to delve further and gain a better understanding of the mechanisms that have resulted in the observed events. In data collection and analysis processes, the researcher has the option of avoiding or using a theoretical or conceptual model to answer the study question (Casanave and Li 2015). The study interview questions (see Appendix E) were informed by prior concepts derived from previous literature and pre-existing theoretical frameworks; this was Theoretical Domains Framework (TDF). There was a risk of researcher bias as a result of my prior experience as an oncology nurse and being a member of the society from which data were collected. I was particularly susceptible to the possibility of ignoring significant

responses, which may have seemed normal to me, and yet could have been significant in identifying the underpinning mechanisms. It was thus necessary to broaden the scope of the investigation away from the researcher's influence. In this instance, using TDF was a helpful tool.

This framework was developed in collaboration with behavioural implementation scientists. It is a combination of thirty-three theories of behaviour, which are grouped into 14 domains as in Figure 9 (Michie et al 2011; Atkins et al. 2017). Initially, it was used in implementation research to better understand what factors impact on healthcare workers' behaviour when they follow evidence-based guidelines. TDF is more of a conceptual framework than a theory. It makes no suggestions for testable correlations between variables or factors. Instead, it serves as a theoretical lens for comprehending the impact of cognitive, emotional, social, and physical environment factors on behaviour (Mieche et al. 2011). It is a useful tool in a number of ways, these include guiding researchers in the formulation of a study questionnaire or interview questions to shed light on the barriers and enablers of the behaviour being investigated (Atkins et al. 2017). This wide range of elements allowed me to explore the barriers and facilitators of UCBD and UCBC, from participants' perspectives.



Figure 9. The TDF domains (Michie et al 2011; Atkins et al. 2017).

Before the actual interview questions commenced the participant was asked a few demographic questions, this helped construct a profile of each participant. Non-verbal behaviour and responses demonstrated during the interview process were recorded to aid with the analysis later (Beattie and Shovelton 1999; Denham and Onwuegbuzie 2013).

#### **3.4.4.1.1. Translation**

Arabic was the first language of both participants and myself, therefore the interviews were conducted and transcribed in Arabic. As these were to be categorised, analysed and presented in English, stringent and rigorous methods were required to ensure the credibility and precision of the data findings. To reduce any risk of bias I used a translator who had no prior knowledge of myself or the study at hand. Guba and Lincoln (1994) give advice on how to ensure trustworthiness in qualitative studies. One of the criteria for trustworthiness is credibility. The credibility of the research is ensured through the processes of back-translation and consulting an independent third party for translation purposes. Translation was conducted after transcripts had been anonymised; interview participants were also made aware of the fact that their anonymised interview transcripts would be translated by a third party in the PIS.

#### **Translation process:**

1. The translator and I read through each participant's transcript to familiarise ourselves with the content.
2. Easy terminology, such as expressions, was translated first.
3. The translator and I reread the content several times, noting our thoughts and making comments for areas needing clarification. This ensured accurate and legible translation.
4. For words that were unfamiliar or ambiguous to us, we used a thesaurus, Arabic to English dictionary and vice versa. Whilst ensuring the continued anonymity of participants, I also sought help from friends and family with regard to certain colloquiums that the translator and myself were unfamiliar with, for example terms rooted in Bedouin culture.
5. Following the completion of the translation from the native language (Arabic) to English, we reverse translated the transcripts into Arabic. According to Bryman and Bell (2007), this switchback between two languages is necessary to compare the reverse translations with the original text version to validate word equivalence.

As the final step of rigour in translation method, I randomly selected 20% of the interview transcripts. I hired a second bilingual, independent researcher who first read the Arabic and did line by line translations of the selected sections. The second translations were compared with the original translations and upon agreement, the sentences were highlighted as verified. This step ensured that the translation was consistent in both versions as per Brislin (1980) and Twinn (1998), and thus, the necessary modifications were made. In addition to

interviews, field observations were very beneficial in presenting a thorough understanding of the events and context.

#### 3.4.4.2. Field observation

Observation is the process of using senses in which the researcher focuses their attention on the activities occurring in the study area. The researcher may ask questions about a particular behaviour or event. Field observation is another important tool for capturing a broad range of activities in order to understand the context in which they occurred (Guest et al. 2013). According to Lashley (2017), field observation adds richness to the study data and is well-suited for complex research designs, as was the case with this study. Combining observation with other data collection methods in qualitative research facilitates a deeper comprehension of the phenomenon under investigation (Maxwell 2009). It is a way to validate whether what was previously understood aligns with what happens in practice (Mulhall 2003). I consider myself a semi-insider researcher in this study as I was present at the data collection sites when the proposal was being developed in 2016. Inevitably, ethical dilemmas must be taken into consideration when observing participants in a research setting. Observational approaches may vary from extremely structured to totally unstructured (Walshe et al. 2012). In structured observation researchers collect data in a systematic manner, activities and behaviour are precisely recorded (Mcilpatrick 2008). The researcher adheres to a set of predefined instructions of what, when and how to monitor before starting data collection. It is especially suitable when the research problem is clearly defined, or a hypothesis is being validated (Walshe et al. 2012). Observation field notes provided contextual, and background information, these further informed the abduction and retroduction.

There is not clear guidance for the recording of unstructured observations. It works effectively when delving deeply into a single situation within certain contexts. The researcher pays careful attention to all events that seem to be relevant to the study problem (Mcilpatrick 2008). It has a high possibility of bias since it is affected by the observer's own values (Walshe et al. 2012). Another way to classify observations is according to the observer's role as a participant or non-participant observer (i.e., whether the researcher engages with study participants) (Gillham 2000). Building on these classifications, an unstructured observation method was utilised to observe participants during the UCBD and UCBC units. Participant observations have the risk of the researcher's presence influencing the behaviour displayed by the participants. Informants may alter their behaviour due to suspicion of the investigator

or because they want to please the researcher, thus they influence the data with their bias. Personal interaction between researcher and participants can also influence the behaviour of participants. To avoid such pitfalls, effort was made to reduce the effects of bias by noting feelings and events in a reflective journal. Field observations were also used as one section of the quilt that formed this method. Staff were observed during the day whilst the UCB team was present and were also observed during the night shift in the absence of the UCB team. I chose to be a non-participant observer, with no control over the observed events (Mcilpatrick 2008). This method was considered appropriate for achieving the study's goals.

Researchers may direct their observations by their initial curiosity (what does the observer wish to learn about the research problem?). As a junior researcher I found that utilising an observational guide, such as Merriam's (1998) and Spradley's (1980) dimensions of descriptive observations, was useful. These two guides were merged and used to capture the observed activities within the study setting (Appendix F). Spradley's nine dimensions allow researchers to describe and record concentrated observations, while Merriam's observation guide adds further explanation of what must be observed within these nine dimensions (Appendix F). This allows the researcher to reflect on the observation components and, if feasible, link them.

During the 10-day familiarisation stage I observed the maternity department for interdepartmental interactions, field notes were taken according to the parameters outlined previously. The purpose of observing the staff before interviews was to reduce researcher bias that may arise. Responses in interviews can have influences on the occurrences I observed, therefore, to remain impartial and avoid bias the observations were conducted prior to the interviews (Mulhall 2003).

Using field notes I tried to objectively describe the research setting in order to convey to the reader what I had encountered and experienced at the location. In line with the observational guidelines, field notes were recorded at the time of the event or shortly thereafter. The interviews and field observation were conducted simultaneously. In some cases, field notes revealed some areas of interests, which were then included as part of the interview questions for further explanation. For example, it was noted in the field notes that the room used for UCB collection was stained with blood on walls. This prompted questions around the space and infection control in the interviews with the UCB nurses.

### 3.4.4.3. Documentary review

Documentary review is also a useful approach for validating data acquired via other data sources such as interviews or observations. It may contribute to a thorough understanding of the study context (Yin 2009). Thus, throughout the four steps of data analysis, relevant documents were reviewed and considered in the triangulation process. Table 10 highlights the advantages and disadvantages of utilising documentary review as a data source for qualitative research.

Table 10. The advantages and disadvantages to recording documentation for review.

Advantages	Disadvantages
<ul style="list-style-type: none"> <li>• They could be accessed frequently, without the authors' consent (Merriam 1988)</li> <li>• Exists independently of the study purposes, thus, eliminating the issue of reflexivity, which necessitates a careful awareness of the researcher impact on extracted data.</li> <li>• No need for any interaction to extract the required data (Merriam 1988).</li> <li>• It offers extensive coverage owing to its wide range of data including various events, venues, and times (Yin 1994).</li> <li>• In comparison to other data sources, document review is more efficient since it costs less time to complete.</li> </ul>	<ul style="list-style-type: none"> <li>• It was created for reasons other than research, thus, they seldom answer research questions.</li> <li>• Retrieval of records may be difficult and access to documents could be purposefully blocked.</li> <li>• Incomplete documentation may imply a biased selection, and the selected papers are likely aligned with organisational rules and leaders' objectives.</li> </ul>

### 3.4.5. CR Data analysis

Semi-structured interviews, documentary review and field notes are useful data collection methods, they require analytical methods to accurately discover the underpinning mechanisms accounting for empirical events. The data collection process needs to be supplemented with data analysis to answer the research questions and allow for causal analysis or meaning to be revealed (Peyrot 1996). In this research, the method of data



analysis incorporated the guidelines by Danermark et al. (2002) and Wynn and Williams (2012). The following section explains how CR analysis was implemented in this research.

### 3.4.5.1. Phase one Demi-regularities

The events explication process aimed to organise and arrange the observed empirical events in a detailed description (Wynn and Williams 2012). This stage is essential to abstract the complex events that generated the studied phenomena (Danermark et al. 2002). To explicate the study's events, I started with transcribing, and translating the 37 interviews. Once transcribed I familiarised myself with the data (interviews, observation notes and documents) by rereading and categorising the information by thematic subject matter. Observational data and document data were useful here enabling me to draw links and triangulate the themes and ideas raised by the participants. The data from this study was extensive, a series of coding cycles yielded a list of 68 codes. NVivo was the chosen software for organise the data obtained from interviews, observations and document data. When the three sources of data supported each other, the data points were grouped together to aid the demonstration of triangulation in the write up. These themes were subsequently used in the demi-regularities portrayal process, which resulted in the formation of five key themes or demi-regularities, as described in Chapter four.

The demi-regularities aided in categorising the main areas of the empirical stratum of reality to explore what participants described, this also laid the foundation work for the deep analysis stages of the study: abduction and retroduction. Table 11 shows the methods applied when I gathered and presented the demi-regularities.

Table 11. Methods of explicating events (Demi-regularities).

<b>Initial themes</b>	<b>Themes subsequently used in the demi-regularities process.</b>
What exactly do the demi-regularities imply?	To bring forth complex events and experiences that shaped the empirical phenomenon i.e., the iterative patterns and trends seen in the empirical realm.
Why is it necessary to "explicate events"?	Because the observed events within the empirical domain (barriers and facilitators of UCBD and UCBC) are not deep enough to answer the research question. They are a part of the whole stratified reality. Explication of events laid the groundwork to identify the structural and contextual factors from which these

	events emerged, and consequently their generative mechanisms.
How does the researcher abstract the "explication of events"?	By tracing the actual triggers and links between events that revealed during interviews, field observations and documentation review. First identified and abstracted the iterative patterns and trends seen in the empirical realm. Then, sorted, and grouped them into broader themes (five demi-regularities)
Outcomes (finding Chapter)	A total of five demi-regularities were determined (Chapter five).

### 3.4.5.1.1. Field observation data analysis

Every day, at the end of data collection, field observation notes were consolidated using Merriam's (1998) and Spradley's (1980) dimensions of descriptive observations as seen in Appendix F. The observation notes were read and reread. Inductive coding was used to code the observation notes. Further comments were added to better explain the codes and nuances of the observation notes. An example of this can be found in the table 12 below.

Table 12. Excerpt of field observation data analysis.

Observation notes	Codes	Comments	Patterns and trends (demi-regularities)
The mother was about to give birth when the UCB nurse approached her for UCB donation. The nurse introduced herself and spoke with the mother for less than three minutes, offering her the donation option. The mother expressed her willingness to donate the UCB unit. The UCB nurse started preparing the UCB collection kit and the harvesting was completed within 9 minutes of the baby's birth. The mother	<ul style="list-style-type: none"> <li>Poor UCB education and recruitment process</li> </ul>	<p>Three minutes are not enough to provide education and obtain informed consent. No educational material provided.</p> <p>Mother still have some questions related to the UCB programme.</p>	<ul style="list-style-type: none"> <li>UCB nurse lacking skills required for UCB education.</li> <li>Mother lacking required knowledge.</li> <li>Interpersonal conflict</li> </ul>

<p>signed the consent form when the unit harvest was completed. No educational materials or Islamic rulings on UCB donation were given to the mother. After some time had passed, the mother called the midwife and asked several questions about the UCB programme, as she was curious to learn more about it... and whether there was any Islamic ruling that would permit this action. Also, the mother was worried about the effects of the donation on her and her child. The midwife said: [you should have asked the UCB nurse to answer all of your questions before consenting to the donation]. The midwife then reassured the mother and answered her questions.</p>		<p>Therefore, she asked the midwife for further explanation</p>	
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After the interviews have been analysed, a second round of coding of the field observation notes was conducted. Patterns and trends (or demi-regularities) that emerged as part of the interview data analysis guided this coding process. Excerpts of the observation notes that explained or supported the patterns and trends in the interviews were coded as in the last column in the table above. The coded observation notes were then used in support of the demi-regularities in the write up later.

#### **3.4.5.1.2. Document analysis**

Access to the contract, consent form, education material was granted in the middle of the data collection process. When the documents were made available, I read and coded the documents once to identify areas of interest. Comments were added to expand on the codes

for further reference later. This coding process raised some additional areas of concern, which influenced the interviews and field observations. For example, in the table below, the contract documentation has noted that personnel collecting UCB units should be trained in the collection procedure. This led to me noting that no training has taken place in the five months of data collection in the observation notes and the inclusion about training frequency with the midwives and awareness of the changes in UCB criteria, demand and collection targets. However, the interview data revealed that training was not conducted, and the midwives were not aware of any updates on the UCB programme. This example is shown in Table 13 below. After the interview data and observation notes were analysed and the patterns and trends, as per the CR analysis process, were identified, the documents were reread again and assigned the relevant demi-regularities.

Table 13. Excerpt of document analysis.

Document	Codes	Comments	Patterns and trends (demi-regularities)
Document LAB-CBB-COL-11.0 (policy): Collection personnel, whether employed by the CBB or not, must have training in key tasks that they perform, and initial and ongoing competency and training must be documented. UCBC Check off should be renewed on a yearly basis and as needed.	Training	No training was provided during the data collection period. The last training was conducted in 2015 by the previous UCB team.  Through the interviews, when asked about the training, UCB nurses mentioned that they were happy to provide training but were not given details on when this would be appropriate to conduct for the midwives despite repeated requests to the PHMD managers.	Midwives lacking training and awareness of UCB programme. Managerial issues: communication

### 3.4.5.2. Phase Two Abduction and Retroduction

Within CR analysis, two crucial stages of analysis are abduction and retroduction. Abduction is the process of revealing plausible explanations or theories based on observations in qualitative research. It entails forming a well-informed assumption or judgement regarding the underlying mechanisms or causes that may be in charge of the observed phenomenon (Sayer 2000). Abduction enables researchers to think beyond the recorded data and develop hypotheses that can be studied further. In CR, retroduction works complementarily with abduction (Danermark et al. 2002). Researchers start with hypotheses revealed during abduction and work backward from there, examining the evidence and deciding if the theory accords with the facts as they have been observed. Retroduction aids in the validation or revision of pre-existing hypotheses, improving their coherence and empirical consistency.

Critical realists need both abduction and retroduction because they provide a way to traverse the complicated reality. Retroduction serves to critically assess and hone already-existing knowledge, whereas abduction aids in the generation of new knowledge and understanding (Sayer 2000). These procedures contribute to the dynamic and iterative nature of scientific inquiry within CR, enabling the creation of stronger explanations and theories about the social and natural world.

Danermark et al. (2002) defines structures as objects or entities that have interactions. The aim of this stage is to find and resolve the existence and nature of things, as well as their interactions and the way they impact upon one another. Extracting existing structures is a necessary step, the social system is an open, complex system with many components and contextual conditions that affect the studied phenomenon. Each specific situation is a product of a complex combination of relationships (i.e., formal and substantial, external and internal relations).

The main aim of the researcher during abduction is to identify the features of a structure and how the structure exists within the study context. To understand these, entities that performed the role of structures of social groups and organisations were sought in the data. Some of the structures were physical and tangible, such as the different participant groups, their spaces, their roles, and the hierarchal structure of the participants. While other structures were unseen, only brought about by asking oneself what must exist alongside these structures? The steps of abduction are outlined below.

- Prior to theorising on the causes behind a chain of events, the linked structures should be broken down into parts such as individuals, regulations, and relationships,

as appeared in the event description. In other words, the basic features of the event must be revealed and their connections and tendencies, which interact to generate the structure's traits.

- Search literature and raw data from interviews and field notes to find additional structures and present links between these tangible structures and unseen ones.
- Ask oneself: if this structure exists, what else must exist alongside it?

The researcher should keep abstracting and isolating inner social connections and structures for as long as the investigation needs.

As previously mentioned, abduction does not immediately shift from empirical events to theoretical extraction. Instead, it heavily depends upon theories as mediators to generate explanations (Sayer 2000; Wynn and Williams 2012). Therefore, a round of literature review was undertaken to examine the theories employed in previous studies, which investigated UCB collection. Articles found in the literature were revisited to specifically look at the theories, if any, that were used. The theories considered for this purpose, included structuration theory, the health belief model.

In Structuration theory, Giddens (1984) proposed that all human behaviour can be assigned to particular structures an individual interacts with. Giddens considered human action as separate from structure and gave distinction between structure and agency. He claimed that agency and structures, though separate entities, are intertwined and are influenced by one another. For example, structures can exist only due to human action interacting with them, and conversely, structures can induce particular human behaviours. Although the distinction between structure and agency was complementary to CR, the theory was found to be unsuitable for redescription purposes. This is due to the fact that Structuration theory focused on human behaviours and did not seem to provide insights on organisations as a whole. As such, structuration theory may have provided insight as to why individuals behaved as they did, it would not have been appropriate in trying to uncover why the UCBBH as an organisation was failing to achieve their desired UCB inventory.

Another theory that was considered for redescription was the Health Belief Model. The Health Belief Model explains why people make particular decisions regarding their health (Champion and Skinner 2008). It implies that people are more likely to take precautions to safeguard their health if they believe they are susceptible to a health issue or consider the issue to be serious. It also suggests that people take health measures if they believe the recommended action will be beneficial, receive cues or reminders to act, and have

confidence in their abilities to do so. This theory was also deemed inappropriate to redescribe the collected data as it mainly focused on the patient. Furthermore, while the health belief model could prove to be useful in abduction as it can unearth the motivating factors in the programme, it is only applicable to the mothers and not the other staff members. As such, it was ill-suited in understanding the barriers and facilitators of the programme that ultimately led to the decline in UCBC.

Research into Giddens' structuration theory had led to other social theories such as institutional theory developed by DiMaggio and Powell (1983) and Meyer and Rowan (1977). Newer iterations of Institutional theory were then explored such as Scott's (2014) New Institutional Theory (NIT), which specifically focused on organisations' systems to be applied to the healthcare field.

NIT explains how regulations, ideologies and social norms govern those within the organisations. NIT is applied in research to study the elements that affect the behaviours of those within the organisation and focuses on the barriers and facilitators of these behaviours. According to Scott (2014), institutions consist of three main pillars: regulative, normative and cultural-cognitive.

The regulative pillar includes the formalised structural aspects of organizations such as rules and regulations that are enforced upon individuals. This form of coercion alerts individuals within an organisation to the boundaries and legality of their behaviours. The regulative pillar comprises of processes such as setting rules, monitoring how others adhere to them and manipulating incentives, punishments, or sanctions in order to direct individuals to behave in a particular way (Scott 2014).

The normative pillar focusses on ideas about professional conduct, education, and accreditation. It is concerned with the norms and values that distinct groups collectively agree to. Through ideas and values of what it means to be part of a specific group, explicit and tacit rules are followed as individuals belong to a discernible group. For example, a nurse's conduct is judged upon their professionalism and the rules of their profession govern their behaviour towards patients or other healthcare professionals. A nurse has specific tasks they must do in order to be adequately providing healthcare. Deviation from prescribed tasks is seen as outside of the norms of their profession and as such is deemed unprofessional (Scott 2014).

The cultural-cognitive (CC pillar) refers to the cultural beliefs and personal values of people within societal organisations. Structures within organisations can be influenced by the cultural beliefs that exist in the organisation (Meyer and Rowan 1977). The CC pillar is mainly concerned with behaviours that are based on completely tacit rules imposed by personal values, identities and belief systems. For example, when interacting with patients, some nurses may prefer to have small talk with patients and ask about their day, while others may prefer to be on task with little personal interaction with patients. Both types of nurses are adequately doing their duties but may have their own tacit rules about personal interactions with them (Scott 2014).

NIT was chosen for the abduction process of this research because it gave insight into the UCB programme as an institution and supported the analysis of the events and elements that affected the UCB collection rate. Using Scott’s (2014) understanding of the pillars that make up the institution, I returned to the data and demi-regularities to identify these pillars within the context of the UCB programme. In doing so, I elicited the different elements within the UCB programme as the institution of interest that interacted with or were influenced by the participants of the UCB programme. In other words, these elements are the structures within the UCB programme that have been explicated using NIT in the abduction process. An excerpt of the abstraction process is presented in Table 14. The combination of these structures formed the beginnings of a mechanism, which required further consideration and manipulation to see the interaction between structures.

Table 14. Example of how structures were developed from codes and raw data.

Codes	Structures
Break current habit - attitude (appropriate preparation, professional communication, stop mobile phone use, show interest to patient) rounds, longer working hours	The structure is connected with the <b>CC pillar</b> (seen through the experiences of the previous UCB nurses, their repetitive patterns and work practices). Midwives have expectations due to the practices of the previous UCB nurses. The previous UCB team had different work ethics and values and they reflect the value of the programme. <b>(Barrier)</b> .
Devote longer working hours for UCB nurses	The structure is connected with the <b>regulative pillar</b> (seen through directives-unwritten rules for UCB nurses).



	<p>Previous UCB nurses used to liaise with the driver (for example, if they needed to change the pickup time for an anticipated UCB collection). Midwives' expectations of professional behaviour were formed as a result of the previous UCB nurses' practices. Therefore, midwives and PHMD head nurses criticise and judge the new UCB nurses for what they referred to as a lack of work ethic. Also, the PHMD midwives were routinely monitored by their manager (head nurse), as opposed to the UCB nurses, who were not monitored on a regular basis. (Barrier).</p>
Lack of supervision	<p>The structure is connected with the <a href="#">regulative pillar</a> (seen through: Control and regulation of UCB nurses). The supervisor is not available and there is a general lack of supervision (Barrier).</p>

The identified structures within the abduction stage are simply a collection of structures that are a set of potential mechanisms and not yet thought of as mechanisms (Danermark et al. 2002). Once all the relevant structures were explicated for each empirical event, the form of what we might call a 'mechanism' begins with the retroduction process. In retroduction, I determined whether the identified structures interacted in the contextual conditions to propose these collections as mechanisms.

Sayer (1992) defines retroduction as an analytical step that seeks to provide the most feasible explanation of the studied empirical event, considering the circumstances of a contextual setting and mechanisms are seldom noticed directly. Thus, retroduction provides a tentative explanation of how the 'structure's emergent features' interacted with the research context to result in the events under investigation as in Figure 10. In other words, this is to answer Danermark's et al. (2002) question of What makes [the empirical event] possible? or what features should the event possess in order to exist in the way it does?

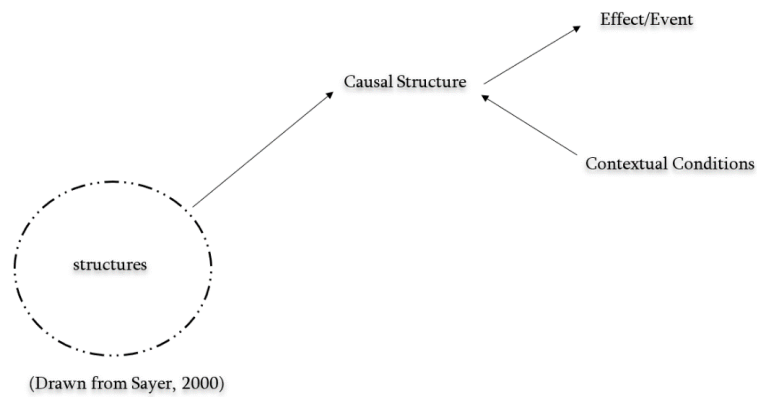


Figure 10. Structure of a mechanism (Sayer 2000).

While abduction analysis is concerned with explicating structures, the retroduction analysis attempts to reveal the generated mechanisms. Therefore, it was important to highlight, that within abduction, there is still some language of 'mechanisms,' this may cause confusion for a novice researcher such as myself. I found some difficulty distinguishing between structure and mechanism. Also, when I attempted to isolate the structures and present them separately, it resulted in complex technicalities that proved challenging to separate, due to the intrinsic nature of structural connections. This may be the reason why many CR scholars regard both terms (abduction and retroduction) as one step (Sayer 2000; Danermark et al. 2002). For this study, within each rough outline of a mechanism the central structure was identified, and the contextual conditions coded. Similar or duplicate mechanisms were deleted and further categorised into groups by the empirical event generated. Each group of mechanisms is a collection of various mechanisms, which combine to form a wider phenomenon within the programme. Chapter five explored these mechanisms by explicating the structures and signifying the interactions between structures and mechanisms to form the overall mechanism group. This process of collecting similar mechanisms and categorising them into groups allowed for the nuance of the data to remain, thus preserving necessary information, while filtering the extensive data.

A vital segment of the retroduction step of analysis is testing the causal power of the proposed mechanisms. Thus, during retroduction presenting the final mechanisms had to pass the testing provided by Wynn and Williams (2012). The researcher utilises empirically observed data to verify that the possible mechanisms are sufficient to reflect reality and to overcome the uncertainty of retroductive inferences. This enables the researcher to understand the contextual circumstances in which these mechanisms operated. Validating the mechanisms as having causal power required a return to the empirical data in order to look for either the mechanisms or their consequences. Wynn and Williams (2012) proposed

a set of questions to determine the most suitable mechanisms to explain the events observed in the empirical domain. Hypothetical situations and scenarios are considered to assess the credibility of the proposed mechanisms (Danermark et al. 2002). Only those mechanisms that best explain the causation behind the empirical events are seen in the findings. Table 15 is adapted from Wynn and Williams (2012) displaying the questions used to test mechanisms. An example of how they mechanisms were tested following Wynn and Williams' (2012) approach can be found in Appendix G.

Table 15. Assessing Mechanisms' Causality by Wynn and Williams (2012).

Question	How test questions are applied
Does the central, causal structure exist in the context of the study?	<ul style="list-style-type: none"> <li>• Ensure that the identified causal structure appears in the study context from the generalised theory by going through the empirical data.</li> <li>• Confirm that the causal structures are not idealisations or exist as an impossible theoretical entity by querying its possibility.</li> </ul>
Are the causal structures affecting the event? Does it have causal power?	<ul style="list-style-type: none"> <li>• Examine the causal structure ascertain that it is a cause of the UCBC reduction rate and not a tangent feature of another causal structure.</li> <li>• Determine the causal structure is not preceded by other structures in the UCB programme.</li> </ul>
Does the causal structure give reasonable explanations for the phenomena?	<ul style="list-style-type: none"> <li>• Determine that the causal explanation is not too distant, which means there should be no missing links or structures accounting for the event specified.</li> <li>• Ensure that the causal structure and the overall mechanism is not affecting a small event within the wider phenomena.</li> </ul>
Do the suggested mechanisms give enough causal depth?	<ul style="list-style-type: none"> <li>• Examine the depth of necessity by looking at the individual phenomena associated with causal mechanisms. Assess that the event would not occur should the causal structure be removed to rule out alternative causal structures.</li> <li>• Assess the priority of the causal structure by determining no other causal structure can account for the same event in a simpler manner.</li> </ul>

### 3.5. Rigour of Research

The standard criteria for assuring the validity, dependability, and objectivity of quantitative research data are not applicable to qualitative studies. This is due to the inherent nature of social objects (Yin 1989; Christie et al. 2000). Therefore, social scientists evaluate the findings

of qualitative studies based on trustworthiness rather than validity. There are four approaches for evaluating the qualitative findings, these are credibility, generalisability or transferability, dependability, and triangulation (Creswell 1998; Christie et al. 2000). However, this study was heavily influenced by Wynn and Williams (2012) CR analytical principles, triangulation was an added step to their framework which was not included in Sayer's (2002) and Danermark et al, presented frameworks (2000). Thus, throughout the data analysis rounds, triangulation was employed to ensure accuracy and minimise bias. The strategies for assessing the research process are briefly addressed below.

### 3.5.1. Credibility

In qualitative research, credibility is comparable to 'internal validity' in the quantitative school. It is known as the degree to which the research processes are trustable and believable (Yin 1989). It reflects on whether the study results reflect reality. Among the various ranges of suggested strategies for enhancing the credibility of qualitative research (Merriam 1998; Yin 2009), the following were used:

- Triangulation: is to employ various data sources to corroborate emerging results. Individual interviews, field notes, and document review were used to triangulate data for this research.
- Checking with colleagues for discrepancies: Areas where some of the data could not be ideally categorised into the pre-assumed categories were discussed with peers and colleagues to ascertain that my response to these areas were not decisions based on bias but legitimately.
- Clarifying researcher's assumptions from the outset: ensuring that philosophical paradigms were understood and adhered to. Reflecting on personal points of bias, being critically reflective.

Also, the framework of Wynn and Williams' (2012) guide to CR analysis obliged researchers to look to the empirically observed events and ask rigorous questions regarding its plausibility as the driving force of events.

While I was familiar with the setting and some participants in the study knew me by name, there was likely to be limited influence on the credibility of the data that was collected from them. When I was at the PHMD prior to the commencement of the PhD programme, I did not work for the participants nor supervise or interact with them in a professional capacity. I was acquainted with some participants due to my physical presence at the PHMD when I developed the proposal for PhD study. While this may have potentially aided the recruitment

of participants, it was unlikely that participants would feel pressured to disclose or omit data. Credibility in the data analysis was further managed through the use of reflective journals and triangulation to ensure that my familiarity with the setting did not affect the analysis process.

### 3.5.2. Transferability

Owing to the subjective nature of qualitative studies, achieving transferability is challenging. It indicates the degree to which an explanation of a certain instance may be applied to other cases, periods, or contexts other than those studied (Maxwell 1992). Transferability can be accomplished when the researcher thoroughly explains the study context, methodologies and presumptions underlying the study (Seale 1999). This way, readers will have adequate knowledge to consider the findings' applicability to other research contexts. In CR, the proposed mechanisms for producing the observed phenomena act contextually. CR places a great emphasis on contextual conditions of the suggested generating mechanisms. For example, CR would not claim that mechanism 'X' produced 'Y' until they are certain of the contextual circumstances of this occurrence.

### 3.5.3. Dependability

In qualitative research, dependability is synonymous with reliability (in quantitative research) (Christie et al. 2000). Qualitative results can be dependable if other researchers verify them and replicate them under the same circumstances (Merriam 1998; Christie et al. 2000). To assess the dependability of a qualitative study, the researcher should consider how closely the findings match the actual data (Merriam 1998). Auditing is another way to ensure dependability in qualitative research (Seale 1999). This implies that the researcher must thoroughly record and elaborate on the study's design, data, findings, and decisions made throughout the study period. Auditing may also be employed to enhance research dependability, researchers critique the strengths and weaknesses of their own work, especially the methodology. Dependability may also be enhanced by modifying the study design when needed, such as when new discoveries arise throughout the study process. Throughout this thesis, including appendices, I have provided detailed descriptions of the research process beginning with the study design and ending with the findings.

### 3.5.4. Triangulation

Wynn and Williams (2012) include an added step in CR analysis unseen in the proposed frameworks of Sayer (2002) and Danermark et al. (2000). Throughout the data analysis

rounds, triangulation was employed to ensure accuracy and minimise bias. This step-in analysis dictates that all methods of triangulation are highlighted in order to demonstrate credibility and trustworthiness in the results of analysis. In this final stage, the uses of various methods and data sources that occurred in every stage of analysis are highlighted. This stage served as a support to the findings, a range of data sources, theories, and methods all led to the same conclusion (Patton 1999).

Wynn and Williams (2012) stated that the basis of triangulation is for two reasons; multi methods are required for critical realist analysis due to the various types of structures. Structures can be theoretical, physical or social and each distinct category of structure carries with it different properties (Danermark et al. 2002). The open system of critical realism therefore requires the use of various methods to view the data in a rounded manner. The second purpose of triangulation is to mitigate the risk of bias (Wynn and Williams 2012).

This study utilised various methods of data collection, from multiple sources. Semi-structured interviews were conducted with participants who represented staff groups directly involved with the UCB programme. Participants from the previous UCB team were interviewed as well as current team members. Finally, participants with varied authority were interviewed. Thus, a well-rounded view of groups' perspectives was taken into account.

Relevant documents were reviewed which offered evidence supporting or refuting participants' responses, such as contractual agreement between the departments and parents' consent forms. These documents provided further information on many of the regulative structures of the UCB collection programme.

Field notes are an added step in data collection, they provide on-the-ground information on the activities and routines of participants observed (Mulhall 2003). Field notes have become a staple in healthcare related qualitative research as they provide a rich description of context and support data collected during interviews (Creswell 2013). Field notes provided context in the data analysis, although experimentation was used extensively to re-imagine or predict the likelihood of events happening with different structures (Emerson, et al. 2011). My experience observing the UCB programme, and my field notes helped the decision-making process during retrodution and empirical corroboration and minimised the risk of personal bias. Field notes also aid qualitative researchers during reflection and when identifying various biases (Rodgers and Cowles 1993). For example, soft skills were not necessarily seen at the interviews, but field notes and observations helped to provide a fuller view.

### 3.6. Ethical Considerations

The codes of conduct for scientific research were enacted to reduce anticipated risk for participants such as injuries or discomfort (Chilisa 2005). It is the researcher's responsibility to safeguard the respondents' identity and privacy by ensuring their anonymity (Silverman 2000). The researcher should also, obtain participants' permission prior to data collection, and to clearly state that participation is optional, and that they may withdraw if they so choose (Creswell 1998).

To conduct this research, it was necessary to obtain prior authorisation from the necessary bodies. Firstly, permission was granted by Cardiff University Research and Ethics Committee. Once this approval had been granted, I communicated with the Ministry of Health (MOH) in KSA to gain permission from the Institutional Review Board (IRB), this conforms to the Saudi law of ethics of law and research on living creatures. The MOH needed to be contacted as the PHMD is under their jurisdiction and research ventures require governmental permission. Following approval from the MOH, I corresponded with the UCBB Research Advisory Council for further approval to conduct the study in that hospital.

Informed consent was ensured in multiple ways: presentations about the research were conducted at several points during the recruitment stage of the study, I was present at the study site should prospective participants require more information about the research, information sheet was personally handed to participants and participants had my contact information should they have any queries. These steps ensured that there was sufficient information provided and sufficient time to allow participants to decide on taking part in the research.

Data collected in the research was also kept confidential in accordance with the data protection and management policies at Cardiff University (2021). Participant consent forms, and data collected is stored in a password protected computer and only made accessible to the researcher and research supervisors. Prior to translation, all participant information was anonymised and in the write up of the research, only participant IDs were used. Data was stored and held for a maximum of five years or until the completion of the research (whichever is sooner) before it will be destroyed.

Some participants were initially hesitant in taking part in the interviews however they were put at ease when I assured them that the interview data would not be released to their



superiors. Interviews were conducted in private rooms and department heads were not made aware of staff's participation in the research.

A small token of appreciation in the form of a coffee voucher was given to participants of the research for their time spent on the research. This voucher was valued at ten pounds, approximately the price of two cups of coffee at the hospital cafeteria and would not be considered as inducement. It is unlikely that this would result in bias in the data provided.

### 3.7. Chapter Summary

In conclusion, CR provides researchers with a theory-driven framework that can be applied when looking for explanations of social phenomena. In CR, reality is understood as being stratified into the empirical, the actual and the real layers of reality. These realities contain events, experiences and mechanisms that make up the phenomenon of interest. CR states that in the social world, objects exist within open systems. Open systems are the compilation of multiple mechanisms that account for the events we can see, measure, touch and perceive. Epistemologically, CR researchers are interested in understanding how these mechanisms function to explain phenomena and their causal roots. In this research, CR was particularly useful in supporting the research process of understanding why the UCB collection rates were decreasing.

The objectives of this study were to understand the barriers and facilitators of UCBD and UCBC from both HCP and parents' perspectives. Qualitative methods were utilised, specifically an explanatory qualitative research design with several data sources. Qualitative research methods were utilised so that I could fully immerse myself in the study context and have a true understanding of what was happening on the empirical stratum of CR ontology. Data was collected using semi-structured interviews, field note observations and review of documentation. Participants were recruited in accordance with ethical guidelines of both Cardiff University and governmental and healthcare officials in KSA. The study context was a UCBC site where all participant groups conducted their tasks and was the site of the PHMD.

Data analysis was described in this chapter in accordance with CR analysis methods. CR promotes the use of abduction and retroduction at the heart of data analysis. Methods used were contingent with the deduction tools used by Danermark et al. (2000) and Sayer (2000). In this framework, the guidance of data analysis follows this synopsis:

- The portrayal of events and experiences of participants; in this study, events and experiences were presented as demi-regularities. Whereby trends seen in interview data and field note observations were portrayed.
- Abduction: This step of abductive reasoning uses established theories to re-describe the collected data. This theoretical re-description brought forth the seen and unseen structures that existed in the study phenomena. NIT was used in this research to identify structures within the UCB programme.
- Retroduction: the explicated structures were further analysed to bring forth possible mechanisms. Thus, structures ceased to exist in isolation, rather, they were thought of as parts of a whole, with links to other structures and interactions with the environment. These mechanisms were thought of within contextual conditions.

The next chapter features the demi-regularities elicited from the data.

## Chapter 4. Findings: Demi-regularities

### 4.1. Introduction

In the next portion of this chapter, a portrayal of the demi-regularities (DR) found from the interviews will be shown. All information provided will solely be based on experiences depicted from the participants' interviews, though contextual background information was necessary at times to explain some of the points raised. The trends and patterns seen in the participant responses account for the empirical layer of ontology discussed in the methodology chapter. Although the data explored here explains some of the phenomena, they do not account for the causal factors influencing UCBC and UCBD rates. This first step in the data analysis revealed the key events and the study context. This chapter presents the participant information and trends and patterns observed within the data. These demi-regularities draw from participant interview data and are triangulated using other sources of data.

### 4.2. Sample

Most of the sample were recruited using convenience sampling methods from two sites. The Public Maternity Hospital Department (PHMD) was the site of UCBC, the antenatal department and midwives were recruited from this site. After receiving ethical approval from the umbilical cord blood bank hospital (UCBBH), the UCB team participants and policymakers were recruited. The PHMD midwives were recruited through purposive sampling methods based on their self-reported UCBC rates (either high collection or no UCBC). In this research five UCB nurses, three UCBBH policymakers, six midwives, five antenatal nurses, five obstetricians, four PHMD policymakers and nine mothers were interviewed.

Table 16 below, describes the demographic characteristics of the participants. The participants' names were not recorded in the tables and their characteristic information is given as a range (age) to allow for anonymity. Important participant characteristics to highlight here are the differences in qualification between the UCB team and the PHMD midwives. The UCB team were all Bachelors' degree holders, whereas the midwives' held diplomas. Secondly, most of the participants were women, which influenced some of the demi-regularities in this chapter. Lastly, the participant groups had vastly different experience

in the field, the current UCB team were the newest additions with less experience of working on a maternity ward than other participant groups.

Table 16. Demographic characteristics of study participants

<b>Participant groups</b>	<b>Participant ID</b>	<b>Age</b>	<b>Gender</b>	<b>Qualification</b>	<b>Work Experience (y)</b>
<i>Previous UCB Team</i>	<i>UCB Nurse 1</i>	<i>50-59</i>	<i>Female</i>	<i>Bachelor's degree in nursing</i>	<i>30</i>
	<i>UCB Nurse 2</i>	<i>40-49</i>	<i>Female</i>	<i>Bachelor's degree in nursing</i>	<i>22</i>
<i>Current UCB Team</i>	<i>UCB Nurse 3</i>	<i>20-29</i>	<i>Female</i>	<i>Bachelor's degree in nursing</i>	<i>3</i>
	<i>UCB Nurse 4</i>	<i>20-29</i>	<i>Female</i>	<i>Bachelor's degree in nursing</i>	<i>3</i>
	<i>UCB Nurse 5</i>	<i>20-29</i>	<i>Female</i>	<i>Bachelor's degree in nursing</i>	<i>3</i>
<i>Midwives</i>	<i>Midwife 1</i>	<i>30-39</i>	<i>Female</i>	<i>Diploma in midwifery</i>	<i>10</i>
	<i>Midwife 2</i>	<i>30-39</i>	<i>Female</i>	<i>Diploma in midwifery</i>	<i>10</i>
	<i>Midwife 3</i>	<i>30-39</i>	<i>Female</i>	<i>Diploma in midwifery</i>	<i>12</i>
	<i>Midwife 4</i>	<i>50-59</i>	<i>Female</i>	<i>Diploma in midwifery</i>	<i>19</i>
	<i>Midwife 5</i>	<i>40-49</i>	<i>Female</i>	<i>Diploma in midwifery</i>	<i>21</i>
	<i>Midwife 6</i>	<i>30-39</i>	<i>Female</i>	<i>Diploma in midwifery</i>	<i>10</i>
	<i>Midwife 7</i>	<i>30-39</i>	<i>Female</i>	<i>Diploma in midwifery</i>	<i>7</i>
<i>Antenatal team</i>	<i>Senior specialist obstetrician</i>	<i>40-49</i>	<i>Female</i>	<i>Obstetrics and gynaecology</i>	<i>21</i>
	<i>senior specialist obstetrician</i>	<i>40-49</i>	<i>Female</i>	<i>Obstetrics and gynaecology</i>	<i>20</i>
	<i>Senior OB-GYN</i>	<i>40-49</i>	<i>Female</i>	<i>Obstetrics and gynaecology</i>	<i>10</i>
	<i>OB-GYN Resident</i>	<i>30-39</i>	<i>Female</i>	<i>Obstetrics and gynaecology</i>	<i>5</i>
	<i>OB-GYN Resident</i>	<i>30-39</i>	<i>Female</i>	<i>Obstetrics and gynaecology</i>	<i>4</i>
	<i>Staff nurse</i>	<i>20-29</i>	<i>Female</i>	<i>Bachelor's degree in nursing</i>	<i>6</i>
	<i>Staff nurse</i>	<i>20-29</i>	<i>Female</i>	<i>Diploma in nursing</i>	<i>7</i>
	<i>Staff nurse</i>	<i>30-39</i>	<i>Female</i>	<i>Diploma in nursing</i>	<i>11</i>
<i>Policymaker</i>	<i>Oncologist 1</i>	<i>50-59</i>	<i>Female</i>	<i>Paediatric haematologist/ Oncologist</i>	<i>30</i>
	<i>Oncologist 2</i>	<i>50-59</i>	<i>Male</i>	<i>Paediatric haematologist/ Oncologist</i>	<i>33</i>
	<i>UCB Team Supervisor</i>	<i>40-49</i>	<i>Female</i>	<i>Master in laboratory</i>	<i>15</i>
	<i>PHMD Manager 1</i>	<i>40-49</i>	<i>Male</i>	<i>Obstetrics and gynaecology</i>	<i>15</i>
	<i>PHMD Manager 2</i>	<i>30-39</i>	<i>Female</i>	<i>Master in nursing management</i>	<i>15</i>
	<i>PHMD Manager 3</i>	<i>30-39</i>	<i>Female</i>	<i>Diploma in midwifery</i>	<i>10</i>
	<i>PHMD Manager 4</i>	<i>30-39</i>	<i>Female</i>	<i>Diploma in nursing</i>	<i>17</i>

Table 17 depicts the mother participant characteristic information. Notably, there were differences in mothers' education status, with some graduating from high school while others had achieved Bachelors' degrees. In addition, most of the mothers were multipara mothers with previous children. Lastly, mothers were mostly housewives, with two participants in employment.

Table 17. The demographic data for the mothers' group.

<i>Participant group</i>	<i>Participant ID</i>	<i>Age</i>	<i>No. of children</i>	<i>Trimester</i>	<i>Donation times</i>	<i>Qualification education</i>	<i>Job title</i>
<i>Pregnant Mothers</i>	<i>Mother 1</i>	<i>40-49</i>	<i>4</i>	<i>Second</i>	<i>1</i>	<i>Bachelor-degree in Sociology</i>	<i>Civil affairs staff</i>
	<i>Mother 2</i>	<i>30-39</i>	<i>5</i>	<i>Third</i>	<i>2</i>	<i>Diploma in nursing</i>	<i>Staff nurse</i>
	<i>Mother 3</i>	<i>20-29</i>	<i>2</i>	<i>Third</i>	<i>0</i>	<i>A medical college student</i>	<i>Student</i>
	<i>Mother 4</i>	<i>30-39</i>	<i>4</i>	<i>Third</i>	<i>0</i>	<i>Grade 12</i>	<i>Housewife</i>
	<i>Mother 5</i>	<i>30-39</i>	<i>4</i>	<i>Third</i>	<i>0</i>	<i>Grade 12</i>	<i>Housewife</i>
	<i>Mother 6</i>	<i>20-29</i>	<i>1</i>	<i>Third</i>	<i>0</i>	<i>Bachelor-degree in Chemistry</i>	<i>Housewife</i>
	<i>Mother 7</i>	<i>20-29</i>	<i>1</i>	<i>Third</i>	<i>0</i>	<i>Grade 12</i>	<i>Housewife</i>
	<i>Mother 8</i>	<i>30-39</i>	<i>2</i>	<i>Second</i>	<i>0</i>	<i>Grade 12</i>	<i>Business</i>
	<i>Mother 9</i>	<i>30-39</i>	<i>3</i>	<i>Second</i>	<i>0</i>	<i>Grade 12</i>	<i>Housewife</i>

### 4.3. Demi-regularity findings

This chapter describes the empirical events and experiences of the participants, which are categorised into trends or DR. These demi-regularities were then concluded and summarised. Five demi-regularities were seen from the data, these were:

- Demi-regularity one: Changes in Market Demand and Collection Criteria
- Demi-regularity two: Knowledge and Soft Skills
- Demi-regularity three: Sociocultural Issues
- Demi-regularity four: Managerial Issues
- Demi-regularity five: Interdepartmental Conflict

### 4.3.1. Demi-regularity one: Changes in Market Demand and Collection Criteria

In 2003, physicians (mainly oncologists and haematologists) lobbied to establish a local UCBB, as the need for UCB units was relatively high. The cost that came along with importing and transplanting UCB units was also high, costing hospitals around \$40,000 per unit. By 2006, local UCBBs were set up and running. Due to the high prevalence of consanguinity (first-cousins marriage) in KSA, a higher donor match is more probable. In addition, banks found that storing the UCB units were cheaper at \$7,000 - \$8,000 per unit.

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**Oncologist 2:** *Also, we do not always have local units available in our national banks, which result in importing international units that are extremely expensive, about \$40,000 per unit if we compare it to the local cost \$7 or 8000.... I believe there's still room for UCB, especially for certain diseases. This is the vision we have here in KSA and particularly in UCBBH due to the high rate of consanguinity marriage (when people marry within their families), however, in other countries, this is obviously not the case.*

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In the background chapter, the fluctuations in UCB demand were explained. The importance of UCB units in the treatment of malignant diseases was diminishing, due to the uptake of alternative therapies. Although much of this is background information necessary for exploring the context of the case, it is raised here as some participants had discussed these changes during interviews.

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**Oncologist 2:** *I think the future of UCB, for the time being, is still a reliable choice for transplantation. Yes, the demand has decreased for example, as I said earlier, we are doing now about 10 UCB transplantation per year while previously, we were doing about 30 or 40. It was around one third of our transplants. So, UCB transplant was very popular, but now with haploidentical and the Matched unrelated donor (MUD) registry option, things have changed... However, transplantation is still the only reliable option for metabolic disorders. and it depends also on the disease itself, so, basically, we decide the best stem cell source based on the diagnosis*

*itself and the availability of a relative donor. So, for example, if a leukemic patient has no relative matched donor and no MUD on the registry yet, then the option will be to use UCB transplantation.... So, yeah, if there is no relative donor then the option is UCB transplantation.*

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Furthermore, some participants highlighted that there was still some importance in continuing to build a solid foundation of UCB units, due to recent developments in therapies using UCB units.

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***Oncologist 2:*** *Also, now, there are various trials on CAR-T therapy. So, they work on the memory part of the immune system... and they replicate these cells, and they reintroduce them to the body to terminate cancer cells.*

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Adding to the national changes in demand explored above, it is worth noting that there was a parallel alteration in the bank's collection rates. Some participants attributed this adjustment to alterations in the UCB collection criteria related to the health of the mother and newborn, such as the exclusion of UCBC from twins and newborn with meconium-stained cord. In 2006, the UCBB was functioning and an exponential increase of UCBC rate was observed, it peaked at 927 units in 2010 (see Figure 1, p. 3). Initially, the aim of the programme was to collect as many units as possible. When sufficient units had been stored, it was necessary to comply with updated international standard for UCB storage and the FACT certification. This was accomplished by modifying the unit's selection criteria to improve future storage quality. The inclusion criteria for UCBCs were made more stringent resulting in 623 units collected in 2011. The alteration of the inclusion criteria was in accordance with what policymakers deemed usable for transplantation. The UCB team participant below explained these changes from their perspective.

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***UCB Team Supervisor:*** *The midwives are still helping us, but our criteria have changed. When we first started as a centre, we were collecting every possible unit... That was a chance for us to practice the collection procedure also, to build a base for the UCB bank. However, things have*



*changed now with FACT standards, we attend courses, symposiums, and education sessions. We gained experience. We have learned that patients would not benefit from the poor-quality units.*

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The inclusion criteria were changed to exclude collection from meconium-stained cords or from high-risk mothers (including those with diabetes, or hypertension,), mothers with cancer in their family medical history and mothers with a gestational period of below 34 weeks. The changes in the collection criteria were implemented with the aim of collecting high-quality UCB units in accordance with the FACT standards. However, the leaders of UCB bank neglected to properly communicate this information to the PHMD staff (who would voluntarily collect the units). A midwife from PHMD spoke of her confusion in the changes that were not well communicated.

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**Midwife 2:** *We were told to collect from all labour cases. To be honest (sigh), what we understood from the nurses, was that the collection criteria has changed as per their manager's orders and I think this what has affected the collection rate, but what is sad here is that we knew this by chance when I asked the UCB nurse why she is not taking the blood and she said: "oh, because we've changed the criteria and this cord is not matching it.*

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The partnership contract specifies that the UCB bank is responsible for communicating any changes to the UCBC policy to the designated collection centre. Until the collection facility is notified and gives its approval, these modifications should not take effect.

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**Document LAB-CBB-COL- 000-Jun/2014:** *Responsibility for updating and archiving this policy rests with the department of pathology and laboratory medicine at the Public UCB Bank and the update will not be valid unless informed and approved by the public maternity hospital.*

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This was not happening in practice. Midwife 2 explained that her awareness of the changes in criteria had only happened by chance, rather than through official communication

channels. Not only was there a change in the criteria, but many participants had been given no understanding of the changes in criteria. Differing participant groups offered experiences that were vital in understanding the bigger picture as more nuanced responses were conveyed. Some participants felt that the change in criteria had unnecessarily affected the collection rate, while other participants did not understand the need for collecting higher quality UCB units; the logic here was if nearly all units are collected, the quality of the unit can then be analysed microscopically later.

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***PHMD Manager 1:** I do not understand! Why are these criteria changing? And how can they expect our support if they are not telling us what to do, and what is going on in this programme?*

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While the change in criteria and demand were known to the policymakers and UCBBH management, there was little knowledge of these changes amongst the more junior staff members, including the UCB nurses and PHMD staff. Lack of knowledge, and awareness of the programme, and the context surrounding it was a common trend amongst many of the policymakers and is the next demi-regularity to be explored.

#### 4.3.2. Demi-regularity two: Knowledge and awareness of UCBB

The following demi-regularity concerns participants lacking knowledge about the programme. A common trend encountered was that participants appeared to have little understanding of certain features that are seemingly necessary for a smooth operation.

When the UCB programme was initiated, the UCBBH management provided briefings on the programme matters such as its goals, expected responsibilities from each partner and the operational practices of the programme. Also, to enhance the staff understanding of the UCB topic, PHMD staff were regularly educated and updated about the advantages of UCB and received hands-on training in its harvesting techniques. However, those briefings or updates did not continue, thus both existing and new maternity staff were not made aware of the programme's intricacies as it pertained to them. The consensus was that the programme benefited only the staff at the UCBBH.

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***PHMD Manager 3:** I know many of the [PHMD] staff are not aware of the importance of this programme. They think that [UCBBH] is the only party*

*benefiting from this programme because they collect these units for their research and not as a treatment for patients in need of stem cell therapy.*

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The PHMD staff had little knowledge of the UCB programme and how the UCB units were used, although the obstetricians had more knowledge about the diseases treated by stem cells sourced from UCB. However, the obstetricians' knowledge is due to their professional training and curriculum, rather than from the programme itself.

Also, the UCB team itself showed a lack of subject knowledge. This was noticed by other study groups, particularly the midwives.

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**Midwife 1:** *The way they [UCB nurses] approach mothers to donate is not sufficient... they need to learn more about the UCBB... why it is important, what for... You cannot just ask the mother after delivering the baby "Can we collect your UCB for cancer patients". Mother needs to know more information to trust you. If you know enough, you can approach mothers better... you will be more confident.*

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Although the majority of the study groups demonstrated a lack of UCB understanding as a subject matter, it was interesting to learn that the UCB team, like all other research groups, lacked knowledge of some basic UCB subject matter. Straightforward questions were asked regarding the transplantation procedure and potential outcomes for patients on the receiving end of this procedure, for example engraftment and graft-versus-host disease. This group of participants also had little knowledge regarding the types of diseases that stem cells from UCB can treat, with the exception of cancer, leukaemia and thalassaemia.

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**UCB Nurse 3:** *... I am not very sure. I really need some education on how UCB has several uses and side effects. I thought it was just to treat thalassaemia and leukaemia even when I tried to read about UCB, I would just search in these two diseases.*

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Also, the UCB team had not received adequate training to display standards of practice as a group. The quote below highlights further that the frequency of the UCB teams' training was

inadequate. They had expected a level of training when they first joined the programme, however the reality was different.

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*UCB Nurse 4: definitely, I would take courses related to the UCBC and stem cells. We were promised when we first hired in this position, but nothing happened. They said they would take us to Barcelona (sarcastically change her voice) for the international UCB conference, but nothing happened. They never sent us either international or national courses. All the updates and courses are limited to our management and the lab staff .... and we are not updated about the banking progress.*

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However, there was a distinction between the previous and current UCB teams. According to interviews, the previous UCB team seemed to be more knowledgeable about UCB and its uses, transplantation procedure and so on, in comparison to the newer team:

Despite the existence of literature-based recommendations for calculating the need for UCB units by population, it appeared that policymakers at the UCBB were unsure of the appropriate size of their UCBB. When asked, policymakers either evaded the question or focused on their main aims; namely they emphasised the importance of increasing UCB diversity to their banks to avoid the costly process of importing units. However, when prompted to provide the number of units they aimed to store, participants did not have any guidelines or resources to assess the required UCBB size to address the needs of the population. Rough aims on the inventory size were given by a policymaker. Although it seemingly was not based on outlined policy or research.

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**Researcher:** *and what is your goal for the size of UCB bank inventory?*

**Oncologist 1:** *I think 10,000 to 12,000 units would be okay for us.*

**Researcher:** *I see, and are there any specific standards or needs on which you based this target, I mean the "10 to 12,000 units" you mentioned?*

**Oncologist 1:** *Well, it comes with experience, I guess, after all, we must continue the UCBC .... because at some point, we will need to discard*

*some old units maybe after 10 years... I think the bank must check the bioavailability of these units and then we must replace them with new ones. And we should not overwhelm the lab with a lot of cryopreservation keeping in mind the community needs and demand... basically we are seeking a variety of HLA typing and this is the aim of the programme.*

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There was a consistent trend across the interviews with mothers: many of them had no idea of the existence of the UCB programme or the benefits of using UCB-derived stem cells. Also, despite the fact that an Islamic ruling was issued in 2003 allowing UCBD and stem cell utilization for therapy within the Sharia, many mothers were unaware that such a fatwa existed in accordance with the observation notes.

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**Observation Notes:** *Following the labor, the UCB nurse approached the mother in bed two and asked if she was interested in donating her UCB. The mother was confused at first since she had never heard of UCBD and assumed the UCB nurse was asking for the blood donation (peripheral blood donation). The mother then proceeded to ask a series of questions about the programme, including the religious stance toward this type of donations, how it was similar to or different from the concept of organs donation, and the potential health consequences of UCB donations.*

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A lack of fundamental UCB knowledge, whether in terms of topics or programme aspects, was cited by several participants as a barrier to UCBD or UCBC. The following section addresses some common misconceptions about the UCB programme, these are related to sociocultural influences.

#### 4.3.3. Demi-regularity three: Sociocultural

This next theme or demi-regularity concerns the social and cultural elements that were communicated during the interviews. Here the experiences regarding cultural and religious beliefs as a motivator or obstacle for UCBD and collection will be summarised. The participants discussed the cultural factors that influenced the UCBD and UCBC, which are outlined below:

- Patriarchy, mixing lineages, and superstitions.
- Islamic ruling, parents' education level and ideology

#### 4.3.3.1. Patriarchy, mixing lineages, and superstitions

One of the main responses from HCPs and mothers when asked why individuals would not donate UCB, was attributed to male dominance. While gender roles and power imbalance between agents is of itself a complicated structure, male dominance and the female experience were grouped within this demi-regularity concerning socio-cultural issues regarding donation. This is because many of the responses concerned the role that husbands played in the decision on donation, these included allusions to the cultural structure within KSA. The decision was made to include male dominance within the umbrella of social and cultural reasons for lack of donation.

Since Islamic law is the basis for Saudi law, a woman of legal age and sound mind is free to accept or decline any medical procedure offered to her without the permission of her husband.

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***MOH Law of Practicing Healthcare Professions Document: "Regulation 19-1. The consent of the rational and adult must be obtained, whether a man or woman or his representative or if the patient is legally incompetent prior to any medical intervention in accordance with the content of the Royal Decree No." 4/2428/M dated 29.7.1404H based on the decision of Council of Senior Scholars NO. 119 dated 26.5.1404H (27 February 1984).***

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Similarly, the UCB bank's policy stated that one of the parents may fill out the consent form for UCBD. Also, the donation consent form (Appendix H) explicitly declares that they require the mother's permission for UCBD.

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***Document LAB-CBB-COL- 000-Jun/2014: In all cases Informed consent for UCBD must be obtained before stem cells are placed in inventory. Informed consent should be signed by at least one of the parents.***

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However, some hospitals in Saudi require the approval of a guardian before delivering healthcare services to women or allowing mothers to consent to medical procedures for their children (Al-Amoudi 2012). This was consistent with the findings of this study, which revealed that some PHMD healthcare providers did not want to upset fathers by ignoring their wishes,

despite the regulation. They felt that consent from both parents was necessary. Obstetrician 1 below was under the impression that both mother's and father's consent were necessary for UCBD.

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**Researcher:** *What about the consent form, who do you think is the authorised person to sign this consent?*

**Obstetrician 1:** *Both parents, I believe, should be involved... it's much easier... the last thing we need is an upset father here.*

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From the nuclear family to the wider society, Saudi males are the primary decision makers for women, as several participants stated. Within the family, the male head of the household decides for the family, as explained by several mothers. Thus, if the husband refuses, the mother must simply obey his wishes regardless of her feelings. This manifested itself in the data, nearly all HCPs echoed the same concept of avoiding unnecessary confrontation with fathers, considering that UCBD is not a life-threatening situation. Regardless of how passionate the mother is about the programme, she must initially obey her husband's demands over her own. Mothers were afraid of potential consequences for them at home if they were to go against the wishes of their spouse, for example, divorce.

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**Mother 5:** *The consequences of such a decision could lead to divorce in some families. It's not worth the consequences... Why do not you just involve the fathers in your UCB education? just tell them about the programme... and save yourself the troubles. I mean, he may ask the wife "why would you donate without telling me" [husband says this]. Believe me, as soon as they're informed, they will not reject the donation because it's a noble deed, and the man's main concerns are protecting his family and feeling respected rather than disregarded. Yes, some husbands are close minded and would not understand. He'll say things like, "I'm responsible for you, even for the placenta's blood, I am the responsible one, why are you donating without me knowing". For some people, the women do not have the rights to make the decision. She just carries the baby to term and that's it.*

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When asked about the reasons why fathers would refuse to allow their wives to donate, a common theme that emerged is a lack of awareness of the existence of the UCBD programme, its benefits, and its uses. Some participants felt that should fathers be included in UCB education sessions, the process of gaining consent may become easier.

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**Mother 4:** *We should educate the men also, just so they understand. It's their right to know this. This way you will get fast consent because the father is already aware.*

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While patriarchy was expressed commonly as a barrier for UCBD, participants also regarded their extended families as having influence over decision-making power when giving consent to donate UCB. Mothers and mothers-in-law were particularly singled out as having a say in a pregnant mother's decision to donate. The older generation would give birth at home with family members delivering babies, a centralised healthcare system is still a relatively modern concept. Participants who raised this as a barrier reported that older women in the family distrusted the healthcare system, they wanted the pregnant mother to listen to their wisdom rather than that of doctors.

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**Mother 5:** *They believe more in traditional medicine, and it was limited to family... So, yeah grandmothers can affect the donation desire and there should be a simple way to inform them about UCBD and respect their experience, .... You know they believe they always know better.*

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Another barrier brought up during the interviews was superstition, parents were superstitious about the procedure. In Saudi culture black magic is a widely held superstitious belief, some parents showed an aversion to donating UCB as they thought it may be used for black magic to harm the mother or the child.

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**Mother 7:** *You know, for black magic to work, usually they need a part of your body, like hair, or a part of your clothes. So maybe by taking the UCB, anyone may use these body parts for evil purposes and do black magic on the mother or child.*

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Nearly all HCPs felt that the fear of black magic, and the proverbial unknown, could be due to a lack of faith or education.

Other superstitious, or particularly culture-related responses were also noted in interviews. The idea that donating UCB suggests a mixing of lineage or genetic material for the donor and the recipient was a barrier encountered many times during the interviews. Many mothers were afraid that their child would become blood brothers with an anonymous donor. In Islam, if a woman were to breastfeed two children who were not related, they would be considered as siblings and thus it would be unlawful for them to marry or procreate. Thus, many participants believed that the same could be applied to individuals who received the stem cells and the donor of said stem cells. The concept of blood brothers in the context of UCBD also seemed to stem from the fact that the UCB is coming from the womb, thus the site of gestation, the process of taking blood from this site makes the child of that birth and the recipient of the stem cells siblings.

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***Mother 3:*** *Some of them are afraid of blood brotherhood in future, the recipient may end up being married to their sibling, because they shared the same blood from the same uterus, without them knowing. And here they are afraid of marriage incest... they measured this in the scale of breast-feeding brotherhood (the idea of breastfeeding a child and they become your child and your children's siblings, due to the fact of sharing the same breastmilk), which originally rooted from Islam, where they cannot marry due to being siblings... Personally, I do not blame them; it's a complicated situation.*

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These points surrounding superstition will be further explained in Chapter five. Many of the participant responses linked to a distinct divide between mothers who were educated to degree level, and mothers who had education to high school level (grade 12 in KSA). Participants felt that misconceptions in culture and religion with regards to UCBD could directly be linked to the mother's education level. Some held the view that a mother's fear was simply due to a lack of education regarding the procedure and its effects.

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**PHMD Manager 2:** *The lack of education is the reason for many cultural and religious misconceptions.*

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However, one caregiver gave more context as to the demographics of the mothers that PHMD provided care for. Geographically, the PHMD is based in an area where the surrounding communities have varied levels of education. However, the minimum education level of participants encountered in this study was grade 12 level of education (A-level equivalent). The social standing of the communities living in the surrounding area is also known locally as middle class. Thus, with the lack of a higher education background, the staff experienced difficulty in explaining the UCBC process, and how it benefitted the wider communities. Not only were there difficulties in grasping the logic of the programme itself, but mothers with a lower educational background also had a higher mistrust of the procedure.

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**PHMD Manager 2:** *The great majority of mothers in this region are not highly educated. Either they are illiterate or have intermediate education or high school level (grade12). Many of them were not permitted to further their schooling, since they married at an early age... so they may never learn about this UCB programme and the uses of stem cells, which they could have learned from school curricula, unlike the mothers who visit the UCBBH for their routine prenatal check-ups. Because of disparities in their social, financial, and educational levels. Therefore, mothers in the PHMD have a greater desire to ensure the religion's stance on the UCBD in order to avoid any possible conflicts with their religious beliefs. They might be concerned about the blood brother concept. They may be terrified, thinking that the recipient of their baby's UCB could become a blood brother to their child. However, there is nothing in the Islam is supporting this notion.*

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The comparison to the tertiary hospital here is notable, UCBB hospital is a tertiary hospital, it mainly takes cases where the mothers are at a higher risk. In addition, the patients that attend this tertiary hospital are typically patients who come from a higher socio-economic background. Whereas PHMD is a governmental hospital that treats low-risk pregnant women and patients that come from lower socio-economic backgrounds. Participants felt it

would be of benefit to include Islamic ruling in educational material and also information about the programme, this could take place during antenatal sessions. This would provide the participants with more clarity about the intentions of the programme. Education on the programme itself, and the educational background of mothers and their extended families, has been a recurring trend in the demi-regularities explored thus far.

#### 4.3.3.2. Islamic Ruling and Good Deeds

The background chapter explained the religious influence on the laws and culture of KSA society. Individuals in this society are highly aware of the consequences of committing actions that are deemed as 'sinful' in Islam. Muslims have a strong belief in an afterlife that is dictated by their actions on Earth. Therefore, every action provides either beneficial or undesired consequences in the Hereafter. The Islamic ruling on UCBC was raised as both a barrier and facilitator when participants were interviewed.

Another barrier to UCBD which was expressed in the interviews was the lack of a religious ruling to permit the donation. Although there was a ruling within the Sharia in 2003 which allowed for UCBD and stem cell usage for treatment, the ruling was not widespread due to the lack of education and use of educational material on UCBD as seen in the quote below:

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***UCB nurse 2:** Have you noticed them [current UCB nurses] recruiting mothers? They don't do it properly. They only do it verbally, and they don't even provide them with the educational materials we developed for this purpose.... The Islamic ruling that permits the UCB donation is included in this material. They would have been useful in the recruitment process and would have saved time.*

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Therefore, participants did not know that donating UCB was 'halaal' (permissible in Islam). When they were told, however, some people still showed scepticism as it was not well known, they would have preferred to see Sheikhs explore the subject publicly.

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***Mother 6:** But for you showing the legal ruling is not enough. Sheikhs (Islamic scholar) must talk about it in public, and this should be documented on videos and TV shows.*

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As a facilitator however, participants believed that partaking in UCBD and UCBC led to good deeds recorded as charitable acts. The Muslim belief that one has a duty to help others in distress was a facilitator for participants. However, this was only valid if the mothers were aware of the religious ruling passed in 2003. Mothers who were aware of the procedure and educated on its benefits for possible participants were passionate about donating, they felt that it was their duty to support social solidarity as a Muslim.

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**Mother2:** *I believe most mothers are not aware of the programme. They (mothers) would not mind donating, especially, that our religion encourages all kinds of donations and giving for good deeds...and Islam is encouraging social solidarity... Although I have the insurance and ability to deliver in a private hospital or in the Security Forces Hospital.*

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Education levels, of mothers and families, were repeatedly raised within other social and cultural issues regarding donation. Education also seemed to be a driving factor for PHMD to continue to collect UCB despite pressures not to. Midwife 2 spoke of her reasons for continuing to collect, for the feel-good factor that helping people provided.

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**Midwife 2:** *When I first started to collect the UCB units, I felt satisfaction... and this has reflected on my mood ... I feel happier because I have contributed to a patient's well-being.*

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It can also be inferred from the above quote, that the midwife was aware of the benefits of the programme, and therefore was able to feel that she was adding to the well-being of people in need. The crucial factor of the above quote was that Midwife 2 had been trained on the uses of publicly banked UCB, which then encouraged the personal sense of accomplishment she described.

In summary, many of the cultural and social structures and misconceptions raised in this demi-regularity ultimately led to fear and apprehension about the programme, procedure and donation itself. The Islamic rooted “good” in partaking in the UCB programme as a donor had been both a facilitator and a barrier for mothers. However, the key difference was

knowing that donating UCB was an Islamically charitable act. Furthermore, midwives who were aware of the charitable links to UCBC were still motivated to collect UCB.

#### 4.3.3.3. Demi-regularity four: Managerial Issues

Within this demi-regularity, managerial issues refer to issues that were related to supervision style, management and day-to-day running of the UCB programme. They include:

- Communication
- UCB nurses' workload and management style
- Workplace practices and environment.
- Logistics issue

#### 4.3.3.4. Communication

Lack of communication was an issue frequently raised in the interviews, this was loosely defined in various ways, e.g., contract policy, status of the programme and the role of policymakers. It is important to note that this study pertained to the partnership between PHMD and UCBB. However, participants sometimes stated that some of the events they mentioned happened to a third partner of UCBB (i.e., other collecting centres). There was a major issue in communication between the UCBB and the collection centres regarding the partnership agreement, this created a case of lack of transparency about the national programme among partners. This breakdown in communication coincided with the discontinuation of the programme agreement between the departments. Although this happened externally to the study context with a different hospital, PHMD policymakers felt that the partnership between themselves and UCBBH should be valued more highly as this was the only collection site for public banking use.

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***PHMD Manager 2:** They lost the majority of their UCB partnership contracts; they had six partners. As far as I know, we are now their only partner; they have serious communication issues, we are their success partner, and they should treat us as such.*

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The PHMD's management blamed the UCBB team for the lack of communication between the two departments. The PHMD management team had made an effort to open the lines of communication and to welcome the UCB team at the start of the programme, however these efforts were not reciprocated. This ultimately led the policymakers in PHMD to assume that

the UCBB team may have already collected sufficient units. Thus, there may be no need to collect any more.

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**PHMD Manager 1:** *Although the UCB bank brought its own nurses and technicians for collection, we opened our doors and gave them full support. We gave them our personal mobile numbers as obstetricians to contact us for any issues ...Unfortunately, they never told us how things are going in the programme!! They never shared any improvement plan with us... I do not understand. Sometimes, the nurses just do not show up to the labour ward and they do not inform the head nurse of their intentions. How can they expect our support if they are not telling us what to do, and what is going on in this programme? ... Maybe they are satisfied with their current collection rate. How am I supposed to know? and why should I bother asking my employees to participate if this is the case.*

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Due to the above-mentioned lack of communication between the two departments, senior participants from PHMD were not included in matters that were within their remit. The only time the departments met officially was at the initiation of the programme. This led to PHMD staff's inaction and refusal to participate in any volunteering or supporting plans for the programme. UCB team policymakers have admitted that there were gaps in communication between their team and PHMD.

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**UCB Team Supervisor:** I will be honest with you, we may have been slacking in communicating with PHMD, but they already know the purpose of collection...and we already explained it in the beginning when the programme started.

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Six weeks after the interview with this UCB team supervisor, she decided to take action and to attempt to repair the strained relationship between the bank and its only collecting facility. However, the UCB team supervisor arrived at the labour and delivery room and did not give any prior notification of her visit. The visit was unsuccessful since she was not able to discuss the departmental issues that were stifling the growth of the UCB programme.

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**Observation Note:** *Today, the UCB team supervisor suddenly turned up at 10:30 a.m. in the labour ward, wanting to see the medical director regarding their intended plans for this partnership programme. The medical director was entirely preoccupied with patient rounds at that time. Luckily, she was able to meet the nursing director. Later, I learnt that the purpose of this visit was to improve contact with PHMD and listen to their concerns about the partnership programme.*

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The fact that the UCB team supervisor decided to visit the PHMD hospital without an appointment indicates a lack of departmental communication (Reflections of researcher).

In fact, many policymakers at PHMD felt that UCBBH were mishandling the importance and value of the programme. Due to the lack of communication from the UCBB management some PHMD policymakers felt that the bank management were devaluing the importance of the programme, leaving the PHMD team dejected. Communication repeatedly was closely linked with valuing the programme.

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**PHMD Manager 1:** *They just email the contract to the (ward supervisor) every two years and she, in turn, gives it to the medical director to sign the contract. We have not met [UCB policymakers] for ages. Sending a formal document like this via email is very disrespectful and diminishes the value of the UCB programme, as if [they are not] bothered.*

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While the above quote reflected the importance of the partnership and the value of the programme, the lack of managerial communication between the two hospitals was interpreted as disrespectful. The contractual agreement between the two institutions is renewed every two years, however this contract is not signed in person, rather the contract is sent to PHMD management in the form of an email. The contract document states that the UCBBH is responsible for informing the collecting facilities of any changes in programme policies, although this was not the case. According to interviews, the collection criteria had changed multiple times and the PHMD team was not made aware of these changes.

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**Document LAB-CBB-COL- 000-Jun/2014 (contract):** *Responsibility for updating and archiving this policy rests with the department of pathology and laboratory medicine at the Public UCB Bank and the update will not be valid unless approved by the public maternity Hospital.*

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In addition, the lack of communication on a managerial level was attributed to the cause of the near closure of the UCB programme. The action that triggered this event was a tweet put out by UCBH announcing their collaboration with PHMD to collect UCB units. This tweet drew the attention of the administration at the Ministry of Health (MOH). They contacted PHMD, questioning this partnership and requested proof of permission from the MOH. While the request for evidence was straightforward, some individuals at the management level at PHMD had taken employment after the initial permission had been given and were unaware of the agreement contract. Therefore, a chain of questioning occurred, ultimately one of the PHMD Managers was able to prove that the partnership had support from the MOH.

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**PHMD Manager 1:** *I confirmed the tweet's validity [that we have this programme in our hospital] and I explained the nature of the programme to my superiors. But I realized I was the only one left on the former management team who was fully aware of this, given that it was also signed by the previous health minister. Imagine if I had not been here, or if I had left or been on leave.*

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Here the lack of interdepartmental communication and communication in handover between staff members at PHMD could have resulted in the termination of the entire programme. The interdepartmental communication issues led to significant consequences threatening the entire programme.

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**PHMD Manager 1:** *They put us in a difficult position with the MOH. The whole programme was at risk of termination, and frankly, we do not have time to waste on this kind of issue.*

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This managerial lack of communication was also observed at staff level (with PHMD midwives or UCB nurses). The UCB nurses felt that even on a physical level, the presence of UCBB supervisors visiting the labour ward would increase morale greatly.

During interviews UCB nurses and midwives explained that effective communication with policymakers was difficult.

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**UCB Nurse 3:** *I think our managers should visit PHMD more frequently to see the labour department and meet with their management. This way the PHMD will notice that our managers respect us and that we are not left alone there. They will know then that we are represented and have support from higher up... whereas now they... regard us as nothing. We are expected to be highly productive and collect a lot of units, but we are not given the proper environment to do so. If we explain why we did not collect as much, it becomes an argument, which will only have a negative impact on our work, they think we are slacking, causing us more stress.*

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The absence of communication from the UCB programme managers was raised as a concern by the midwives in PHMD. The below quote shows that the chain of command was not clear with regard to exchange of information and knowledge sharing between the two departments.

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**Midwife 1:** *So, when I decided to look for the contact details of their supervisor to inform her about some issues with the UCB team. Unfortunately, I could not find any way to contact her (UCB team supervisor). I mean... this blood is rich with stem cells that may save someone's life... They have to show that they care and are serious.*

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The partnership agreement between PHMD and the UCBBH stipulated that the UCB team were responsible for training PHMD staff and communicating with them regularly regarding matters that pertained to their involvement. The UCB team were responsible for training PHMD staff on UCBC procedures so that the volunteers could participate freely. However, this

was not the case as UCB management did not communicate with the PHMD and thus did not execute the terms of the contract.

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**Document LAB-CBB-COL- 11.0 (policy):** *Collection personnel, whether employed by the CBB or not, must have training in key tasks that they perform, and initial and ongoing competency and training must be documented. UCBC Check off should be renewed on a yearly basis and as needed.*

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Midwives were not regularly updated with regard to harvesting and changes in criteria; this was interpreted by the midwives as a lack of commitment.

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**Midwife 5:** *To me, it's not fair to know about the modifications in collection criteria after I already completed the unit collection. It is really frustrating... I just found out that the nurses excluded the diabetic mothers from the list, once I finished the work.*

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The absence of necessary communication meant that UCB units were unnecessarily discarded. Also, midwives were less likely to collect UCB, they were uncertain of the inclusion criteria and felt apprehensive about collection fearing their efforts would be futile. Apart from wasting the units, the ambiguity in the UCB programme contract and poorly defined duties left one group of policymakers confused about their own role in the programme. Obstetrician 2 was under the impression that as midwives were trained in UCBC and UCB nurses were present in the labour ward for that purpose, there was no need for them to take part in the programme. Missing out on the potential benefits they can add to the programme.

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**Obstetrician 2:** *Look, I have a full schedule, I think I can start teaching mothers about UCBB during prenatal visits, but I need to understand what I should do and how can I take a part, because I have my own responsibilities as well and I may not be able to always help.*

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Another consequence of poor communication was that midwives believed they were just volunteering and were not in charge of collecting UCB units. This, however, contradicts what was stated in the contract, since it seems that PHMD staff were not just volunteers, they were also in charge of collecting the units.

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**Document LAB-CBB-COL- 000-Jun/2014 (contract):** *PHMD staff who are checked off for UCBC procedure will be responsible for the UCBC procedure.*

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It is important to mention that the previous UCB nurses worked under the same management, however, the collection rate was higher compared with the current rate. According to PHMD staff, the previous UCB team had higher productivity, they maintained lines of communication with the midwives and the ward supervisor.

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**Midwife 2:** *We should get some updates, just like the previous team did...They used to tell us how many units were collected and how many were for storage and the units that were successfully transplanted... this was very encouraging news for us to hear... unlike now, we know nothing.*

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While PHMD staff felt there should be a level of collaboration between the two teams, the consequence of the lack of communication between them led to unrealistic expectations. UCB nurses expected the midwives to notify them when a mother was in the latter stages of labour so that they could initiate the recruitment process for UCBC.

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**UCB Nurse 3:** *Couple of the midwives will let us know when a baby is delivered but majority of them will deny us and when we ask them why they have not called us they say it's your job to be here.*

**UCB Nurse 4:** *Sometimes they (midwives) are uncooperative. I tell the midwives to wait for me just for a few minutes so that I can prepare the UCBC set, but by the time I arrive, she'll have already removed the placenta.*

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While UCB nurses felt that it was necessary for midwives to communicate with them about their patients during delivery, midwives felt that appropriate preparation during their working day would be sufficient to collect adequate UCB units. To the midwives, UCB nurses' lack of preparedness was the reason why UCBC was low. This poor communication level between the two teams turned into a form of personal conflict and tension. This, according to participants, led to decreasing collection rate.

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**Midwife 2:** *They (UCB nurses) should not wait for the midwives to call for them to perform their duties. And as soon as they arrive, they should go through the wards and determine which cases are in active labour to be ready and prepared for collection. I'm sorry, but they should not wait until after the mother gives birth to prepare for collection, expecting me to call them... That's not my job.*

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This fraught relationship between midwives and UCB nurses is a result of other barriers and not just the communication barrier. Communication between and within departments covered various forms and garnered many consequences. However, findings revealed that communication was linked closely with lack of knowledge and education. Through the explication of findings, many gaps in knowledge which were seen earlier are a consequence of the fraught communication channels observed here.

#### 4.3.3.5. UCB nurses' Workload and management style

UCB nurses felt that their workload was too high for them to effectively educate mothers during antenatal appointments, walk the wards and collect UCB during labour. The workload of the UCB nurses was a direct result of the team size and the different sites they were required to work at. UCB nurses were allocated to be either at site one: the PHMD, which was the only public collection site available, or site two: the UCBBH in the delivery ward and blood donor room. This was a major barrier for UCB nurses, three UCB nurses were covering a number of different hospitals in addition to their daily workload. Participants found that it was not possible for one UCB nurse to have access to all patients in the delivery ward (for collection) and the outpatient department (for mothers' recruitment). This was particularly the case at PHMD due to the sheer number of patients that give birth there. The workload for a single UCB nurse on the ward meant that it was impossible for her to drop into antenatal appointments to raise mothers' awareness and aid recruitment.

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**UCB Nurse 1:** *Sending one member of staff to each collection facility is not enough. They should send two of us – one to recruit mothers from the antenatal ward or prenatal clinics so parents have enough time to give informed consent and the other to be present in the labour room for collection.*

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The UCB nurses' mandated tasks were not the only addition to their workload, UCB nurses explained that they would often be relocated to complete tasks unrelated to UCBC. A UCB team supervisor had started to use UCB nurses to cover staff shortage in blood donor rooms rather than using them in a UCB related role, such as public awareness.

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**UCB Team Supervisor:** *We are currently short-staffed; I only have three nurses on my team now. I sent one of them to cover the delivery ward in UCBBH, however I sent her elsewhere today to cover the awareness day held at the North Tower. Then, I sent the second nurse to our lab for blood donors' assessment, and the third to PHMD to collect UCB.*

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Thus, the UCB nurses were faced with reutilisation, they found themselves in an assisting role rather than fulfilling a meaningful role within the programme. Consequently, the UCB team were not able to plan and conduct events or give talks to raise awareness about the programme, this resulted in mothers having a poor understanding of the programme.

Due to the nature of the UCB nurse role, the UCB team were answerable to two departments: nursing and lab departments. The nurses' daily tasks were undertaken in the lab department, however, their evaluations were completed by the nursing department, which was based in UCBBH and did not have knowledge of their daily work.

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**UCB Nurse 4:** *The most confusing part is that our annual performance appraisal is conducted by the nursing department. We struggle to ask the question of who is our boss? What shall we do in case of conflicts? We are not supported by either management.*

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The dilemma of sitting between two departments resulted in UCB nurses struggling to accomplish tasks that would have led to the progression of their careers. The UCB nurses also had to endure the remote micromanagement of UCB team policymakers, this prevented staff from having a level of autonomy over their daily tasks particularly when it came to communicating with individuals outside the UCB team.

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**UCB Nurse 1:** *The consultants had a nice professional relationship with us (the previous team) and usually, if they could not reach policymaker, they contact me to proceed the necessary paperwork for a unit that matched with one of their patients ... if we respond to these requests ... then her anger becomes so obvious ... She may say something like... [Why would they call you in the first place? ... They should have called me rather than you]. Actually, we [UCB nurses] cannot release any paper without her signature... She is insistent that we stay away from any interaction with physicians.*

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Instances such as those outlined in the above quote can cause stagnancy in communication, especially as effective communication from the PHMD team is vital for the efficacy of the programme. Such requests from the policymaker can hinder collection and participation from the voluntary teams. As this policymaker insisted on being involved in communication between UCB nurses and obstetricians, another layer was added to the already fraught interdepartmental communication. This hindrance was directly attributed to a policymaker as described below.

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**UCB Nurse 1:** *Everything is under the control of one person, like an Octopus!*

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In addition to stalled interdepartmental communication, this micromanagement approach led UCB nurses to assume that their creativity was being stifled and that they were losing their autonomy.

#### 4.3.3.6. Workplace practices and environment

As a consequence of the interpersonal conflict, which is explored in the subsequent DR, PHMD Manager 3 withdrew privileges that the previous UCB team had enjoyed, such as the

lounge room within the labour ward. This resulted in the UCB nurses having only one room (instead of two rooms, one for blood collection and one as a UCB staff lounge room). Currently, the only room allocated to the UCB team is both a staff room and UCB storage room. For UCB nurses, the lack of a supervisor meant that they spent a large portion of their time on the labour ward in unsanitary conditions. There was also a heightened risk of contamination in the UCB units collected, especially when collection kit supplies are stored in the same environment as the UCB units.

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**UCB Nurse 5:** *The management need to see the working environment in which we work.... We sit in a very small room (150 cm by 70 cm) with all the blood units as you can see. It is filthy with blood splatters on the walls and the weighing scale... seriously, they need to come look at this room specifically. We need them to be aware of the issues and problems we are dealing with.*

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These conditions, they argue, if seen by UCB leadership, would lead to the improvement of their breakout space. Three UCB nurses indicated that the state of the room assigned to them, and location, was symbolic of their value to the UCB leadership in general. I noted my observations of the room:

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**Observation Note:** *The space labelled as the UCBC room was very small with barely enough room for a single individual to work or sit in seclusion. There were some blood stains on the walls of this little room. Interestingly, this was also the space designated for UCB nurses' coffee breaks. The UCB Nurse was sitting in that room, close to the scale that measured the weight of the blood bags, drinking her coffee.*

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UCB nurses consequently felt that they were unwelcome at PHMD, they interpreted the room allocation as a visual representation of their value at the hospital. They also felt that there was little managerial support for them, they felt uncomfortable complaining to their supervisor about their position, which affected their collection rates.

The UCB nurses felt patronised as their opinions were not heard. They were blamed for the reduced UCBC rate by the UCB manager, who has refused to listen to how the change in collection criteria and demand has impacted UCBC rates according to the quote below.

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*UCB Nurse 2: ... with the new criteria, we may collect 10 units per day and only two of them meet the storage criteria. Some days we end up with no single collect UCB unit.... We have been blamed by manager, [why has the collection rate decreased?] ... I know nothing about the microscopic quality of the units unless the lab technician informs us on the next day. I can only decide the tangible criteria such as the blood volume, the baby's birth weight, and the mother's medical history, but not the microscopic criteria such as the neutrophil count until the lab results show up. I explained all these factors to our programme director, but she does not want to understand. She keeps blaming us for the low collection and storage.*

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Midwives frequently indicated that they would limit the number of units collected because there was a sense of job insecurity and dissatisfaction, this was caused by the lack of managerial support. For PHMD staff, UCBC was voluntary and at times midwives felt apprehensive about engaging in voluntary procedures which could result in blame. This sentiment was outlined by the majority of midwives.

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**Midwife 5:** *I am someone who has been questioned when attempting to collect by [PHMD Manager 3] and was told that this is not my job... so why would I put myself and my job at risk?*

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This indicates that it was difficult for midwives to participate in the programme due to their manager. The midwives indicated that PHMD Manager 3 was against facilitating the programme, this lack of cooperation had added to the culture of workplace blame which inhibited UCBC. For midwives job security was at risk if they were to go against the wishes of the PHMD Manager, due to their occupational fears they ceased collaborating with UCB nurses and thus stopped collecting UCB.



The midwives that were concerned about job security were foreign midwives, they felt less protected in the Saudi workplace. Therefore, when explicitly told to stop collecting UCB, these midwives adhered to instructions despite other midwives' continued participation. The foreign midwives expressed the feeling that they were vulnerable professionally and felt that it was safer to follow what they were told. Some Saudi midwives reported that they adhered to direct instructions from management regarding UCBC, whilst others said that they would continue to participate in the programme as their motivation was to increase their 'good deeds and moral standing.

#### 4.3.3.7. Logistics issues

During interviews, participants highlighted the fact that the UCB department was difficult to contact during certain times. This was mainly due to the logistical operations of the UCB department. It had been agreed that the previous UCB team would be able to begin working from the collection centres without having to register their attendance at the blood bank. However, UCB nurses are now required to do so prior to proceeding to the collection facilities. UCBBH had provided a driver for the team, to facilitate the commute. This transportation service was designed to take them from UCBBH at 8:30 am and back to UCBBH between 2:30 and 3 pm. There was only one driver with no possibility of cover, therefore the driver was vital to the daily workings of the UCB team. The previous UCB nurses were spending nearly seven hours per day at the collection centres, recruiting donors and collecting UCB units. While the new UCB team now loses about three hours of their working day commuting between the two facilities. This may have affected the number of UCB units collected.

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***PHMD Manager 2:** They (previous UCB team) were showing up early in the morning. Then, in the afternoon, transportation was arranged to take them back to the UCBBs and hand over the units.... They now had to pass by their workplace... I really do not understand!! Do you know how far apart the two hospitals are? And how long will it take them to get in here? God!! That is a lot of time that could be spent on collection.*

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This was also corroborated by a midwife:

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***Midwife 3:** I believe it's not always their [UCB nurses] fault that they do not show up at the site. No, there are transportation issues, for example*

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*if their driver is on holiday or calls in sick, they are unable to attend. However, they do not even let us know until we see them next.*

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The absence of the driver for emergencies or holidays meant that the UCB nurses were unable to attend PHMD for the duration of their absence. As the service of the driver was unreliable, as expressed in interviews, the UCB nurses' presence in PHMD appeared erratic to midwives. Units collected by midwives were sometimes discarded. The UCB nurses did not inform the ward supervisor at PHMD that they were unable to collect units prior to their expiration due to transportation issues. This led the midwives to feel their efforts were futile, it made them question the value of continuing with collection. The midwives' main complaint was that the UCB nurses would not inform the PHMD team of their absence and they interpreted this lack of communication as an affront to their partnership.

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***PHMD Manager 3:*** *Is this the professionalism they've learned? ... They do not even respect my authority as a manger, I mean come on, we're talking about a contract here, and I am expecting them to show up regularly on time! I think the issue here is they do not have a supervisor to assess their performance....and listen to our concerns.*

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Superficially there appears to be a clear barrier in the day-to-day operations of the UCB programme. The inconsistencies of the UCB nurses' working hours and the unwillingness to disclose their whereabouts led to midwives discarding units that had been collected. It discouraged midwives from collecting UCB as the UCB nurses did not seem to value the extra work that the midwives had undertaken. This lack of appreciation can be seen below:

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***Midwife 5:*** *If they are not eager to accomplish their work... if they do not care, why should I bother?*

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For mothers, logistical issues also inhibited effective UCBC practices. Participants raised concern over the lack of electronic medical files, or a system for pregnant women's information to be easily obtainable and accessible. Therefore, informed consent during pregnancy, where the mother has time to deliberate over the decision to donate, was not

easily obtained. This raised ethical questions about the validity of the method for obtaining informed consent.

In addition to the issue of informed consent, another consequence of the lack of a systematic filing system (electronic or otherwise) occurred when unregistered mothers came into the labour ward to give birth. If mothers are not registered then UCB cannot be collected, there is not enough time to obtain their full medical history. The medical and gestational history of the pregnant mother is necessary for UCBC as all donors need to fulfil the criteria before donation. An incomplete medical history would nullify their willingness to donate. In some cases, UCB nurses explained that they would obtain medical history verbally, thus lengthening the process. This is a significant barrier, participants reported that PHMD often delivered babies of unregistered mothers (88% of total deliveries), as shown in Table 18 below.

Table 18. The total number of births at PHMD in 2019. (Source: PHMD statistics document).

Year 2019	Total deliveries per month	Un-booked cases	%
January	576	523	90.7
February	471	391	83
March	557	473	84.9
April	547	450	82.2
May	581	532	91.5
June	557	518	92.9
July	596	531	89.1
August	566	505	89.2
September	563	510	90.5
October	591	520	87.9
November	529	452	85.4
December	553	486	87.9
Total	6687	5891	88

The lengthened process of obtaining mothers' medical history is a potential barrier to UCBC as the lone UCB nurse had to devote more time to one patient and had less time for recruitment, this added to her workload. This medical history is important ethically as well to ensure that the collected units are appropriately documented for use later, and that they meet the quality criteria.

Mothers who give birth in a private hospital, and want to donate their UCB units, are responsible for organising the transportation of the kits and the UCB unit. This was an added issue which deterred them and UCBC was not deemed as a priority.

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**Mother 1:** *They (UCBBH) were supposed to arrange transportation for my UCB unit, and they should have sent me the collection kit rather than making me chase them down. Luckily, my sister was with me, and she took the unit to them; otherwise, it would have been thrown away.*

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UCBD was thought to be a charitable act, however, the difficulties that arose due to UCBD became an obstacle that mothers were not willing to deal with.

#### 4.3.3.8. Incentives and Motivation

The next trend commonly discussed by participants was with regard to issues around management style. This was mainly with regard to the decisions regarding incentives and benefits on offer for those who successfully took part in the programme.

Participants outlined occupational motivation that would act as an inducement to participate in the programme. The most notable of the proposed ideas included training in a CME credit course, various courses are accredited in KSA and these help participants to further their careers. CME hours in any field is necessary for HCPs in Saudi to accumulate to renew their caregiver license every 3-5 years. Therefore, a free CME course would be an attractive incentive for all midwives to partake in the UCB programme.

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**PHMD Manager 3:** *Training is one of these motivations ... send them (midwives) to different courses with accredited CME hours ... courses based on their interest. For example, personally, I like administration courses... This could motivate the midwives and obstetricians to participate.*

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In addition to the CME hours incentive, extra paid days off in exchange for UCBC was proposed as a welcome incentive for midwives. Midwives felt that extra days off would be more beneficial to them especially since those other incentives, such as monetary incentives, would take time to process and days off were a more attractive incentive. Midwives also felt that if there was a way of including titles and specified roles for midwives, the midwives would be more likely to be invested in the programme as a part of their own professional development.

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**PHMD Manager 1:** *They may give training courses regarding the UCB programme and certify the volunteers with titles such as UCB collector or call them a specialist UCB collector... I believe the volunteers will feel proud and will be motivated to collect. This is what we do with our breastfeeding programme.*

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The last time the midwives were included in any educational awareness of the UCB programme was in 2015. In 2015 there was a UCB awareness day, the day was disappointing for some of the PHMD staff. They were led to believe that they would receive substantial rewards for their contribution to the programme.

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**Midwife 7:** *They [midwives] even prepared a corner to introduce their role within the programme. Unfortunately, all they got was appreciation letters and none of their simple expectations were achieved. It was such a shame. They were disappointed and felt played.*

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Instead of receiving tangible rewards that could further their careers such as certification of competency, a title of being a qualified UCB collector, or simply personal, authentic recognition from management on the amount of work they had completed, the midwives were given a general letter of thanks. This broke all the previous promises that had been made to the team.

Midwives felt that they were entitled to extra workplace benefits for UCBC. For example, they thought the UCB nurses had promised to arrange for off days with PHMD management in exchange for UCBC. However, from the UCB nurses' perspectives, no promises were made by management to the midwives, rather the midwives spoke to the UCB nurses and suggested possible motivators and incentives. The UCB nurses promised to relay their sentiments to their superiors. Midwives' requests were denied by PHMD authorities due to staff shortages.

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**UCB Nurse 2:** *...we said that we are going to arrange that (day off permission) with PHMD management as a reward for the UCBC. At first,*

*that was possible with the previous [leader], however, the current [leader] has stopped this incentive.*

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This shows the consequences of lack of communication and a lack of managerial structure. The midwives did not give their suggestions to their line managers or UCB line managers, they spoke to the UCB nurses instead. There seems to be no other avenue within which midwives can give suggestions to their superiors. In addition, the PHMD were not willing to allow UCBBH to continue utilising their human resources without compensation. According to PHMD Managers, incentivising midwives by offering days off in exchange for a certain number of UCB units seemed to benefit only the UCBBH.

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***PHMD Manager 2:*** *I will not compromise my human resources for another hospital favour. What would I get if I gave the midwives a day off to collect the UCB units?*

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This combination of communication, workload and incentives meant that PHMD's midwives were demotivated and had little desire to take part in the programme. This evasive tactic used by those with authority (managers) led to a feeling of futility in the UCB team and meant the midwives felt they were being misled. Besides being bad for team morale and belief in the programme, this lack of effective communication from those with authority caused the midwives to doubt the promises they made. This in turn, prevented midwives from continuing with UCBC.

On the other hand, the UCB team had experienced failed promises, particularly when it came to furthering their careers. UCB Nurse one was assured that she would soon be promoted, however that promotion never came.

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***UCB Nurse 1:*** *... they gave me the job title of UCB Coordinator; however, my salary remained the same. Although this, I did not mind as they promised me this would change with time, as soon as things started to settle... I was back to be a staff nurse 1 on grade 8, the same as the new nurses ... before, at least I had a title (UCB coordinator), but ... I was stripped of my title, and the salary that I was promised.*

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Five years later, UCB Nurse one was still in the same position, as a result other UCB nurses lacked motivation and therefore felt less invested in the programme. This poor leadership proved to be a potential barrier to UCBC as UCB nurses felt despondent. UCB nurses knew that collecting UCB was their chief role, however they had difficulty in completing tasks and a little appreciation would have been welcome. This was compounded by the feeling that their careers would remain stagnant, with little likelihood of progression.

The UCB nurses' dissatisfaction was attributed to a lack of appreciation and career advancement opportunities. When this was coupled with their exclusion from departmental meetings, nurses tended only to perform the bare minimum required for their position. In essence, nurses felt that they were there just to be collectors, rather than to be part of the programme. UCB Nurse three below summarised their position by questioning:

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**UCB Nurse 3:** *When our departmental meetings are held, we should be included as team members and understand what is going on in this programme, rather than being treated as collectors only... I am a part of the programme and I deserve to be treated with some dignity and respect.*

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Here is an example of how a lack of knowledge intersects with managerial issues (demi-regularities). Agents with authority in the UCB team are responsible for updating UCB nurses, however they failed to do so; the UCB nurses were simply disregarded and unaware of structural changes to the programme (i.e., unaware of changes in UCB demands).

More importantly UCB nurses reported that their daily duties prevented them from enhancing their careers. They felt that the procedure of UCBC was a simple task that could be done by lab technicians (less qualified than nurses). Also, many nurses stated that they felt their careers were stagnant due to the monotony of their job.

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**UCB Nurse 2:** *The UCBC procedure can be performed either by a nurse or a lab technician.... assigning a nurse for this task will impact on her experiences and skills ... so, they should consider our professional development.*

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The UCB nurses felt vulnerable as they were anxious that the blame for falling collection rates would fall on them.

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**UCB Nurse 5:** *When the collection rates decreased and manager started questioning us about the low rates, we defended by saying that the criteria changed..., this was so stressful ...I mean being constantly blamed for things over which I have no control.*

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The lack of professional growth for UCB nurses was also ascribed to there being few aspirational positions open to staff. There was little evidence of the possibility of promotion within the programme, UCB nurses felt there was no point in trying to climb up the professional ladder as they would be rejected, this led them to be less invested in improvement of the programme.

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**UCB Nurse 4:** *I'm fed up with this stagnation ... and then what? HAH... I really need to move up the ranks and get a higher position. Why should I bother to improve things? HAH... a little bit of inspiration or hope would not do any harm.*

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When the midwives were asked about their reservations in collecting UCB units, they often cited workload to be a main barrier. Their main concern was the safety of mothers in labour, as each midwife was responsible for two mothers in labour at the same time. They felt their efforts were better placed by observing their patients during labour rather than preoccupying themselves with UCBC, particularly as it was a voluntary role.

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**Midwife 1:** *No, I am in charge of two patients, and sometimes both of them are in active labour and may give birth at the same time, and each unit takes me at least ten minutes to collect, and I cannot risk my patients' lives.*

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Not long after this quote, the same midwife became stressed and began to vent about the UCB nurses. This piqued my interest, and I wondered if this rage was related to a hidden reason for not assisting in the collection of UCB units other than the workload.

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**Midwife 1:** *Why should I bother if she [UCB nurse] does not value this programme? I will not bother calling her to do her job, and then what? What should I say? "Oh, hey the patient gave birth finally you may collect the UCB unit now!". They [UCB nurses] do not even ask us if I am willing to do so; they think it is my responsibility to summon them for their work. Am sorry, no, it is her [UCB nurse] job to 'walk the round' and keep herself updated on the labour progress of these mothers... not mine. Who is she to think that I am responsible for summoning her to do her own job? Is it simply because she works for UCBBH (sarcastically)?!*

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Particularly when several midwives mentioned that, while workload contributed to midwives not being interested in UCBC, the main reason was the lack of communication and perceived respect from the UCB team.

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**Midwife 3:** *No, I do not think so. This matter is deeper than workload, they should have better communication with us including their supervisor or manager. They are ignoring us as if we never signed any contract.*

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Many midwives have volunteered to help with UCBC, particularly during the previous UCB team's time. They have, however, changed their stance, and not just because of their workload. This indicates that at the empirical level workload is a major factor in this study, however it only becomes a barrier when it is coupled with other features of this demiregularity such as lack of communication. The workload of midwives when compounded with fraught interdepartmental communication led to midwives' aversion to collecting UCB, they then prioritised their daily tasks and patient safety. Connections can be seen between communication, knowledge, and managerial elements of the UCB programme, this compounds to less PHMD contribution in the UCBC.

#### 4.3.4. Demi-regularity five: Interpersonal Conflict

This next demi-regularity concerns the conflict between staff members and managers of differing departments and between managers and their staff. During data collection and coding it was found that many of the conflicts that occurred were the result of grievances explored in other demi-regularities. Due to the cumulative nature of this DR, it was necessary to revisit some of the experiences of participants that were described earlier to present the empirical causes of conflict.

In this DR, the experiences of participants with and from the previous UCB team were included also. This is because many of the participants had mentioned the previous UCB team when explaining their experiences at the time of data collection.

##### 4.3.4.1. Champions and Advocates

During interviews, the PHMD participants often commented on the practices of the previous UCB team and how the two departments worked together to collect UCB. Participants often used their experiences with the previous team to explain their frustrations with the current team. Thus, this section explores the practices of the previous UCB team who were given the moniker “Champions and Advocators”.

The previous UCB team had more experience in the nursing field, thus they were better equipped to work alongside the collection facilities and with mothers. According to midwives, the inexperience of the new UCB team (nurses were recent graduates) led to a lack of finesse in soft skills. Soft skill is the term used to describe actions and communications possessed by an individual which enables them to work harmoniously with others, such as professional interactions and introducing oneself. Lack of these skills could inhibit the recruitment process and the day-to-day operations of the programme. The experience of the previous UCB team meant they had witnessed patients in oncology wards suffering due to a lack of matched stem cells donors. These emotive motivators also combined with the religious benefits that were described in the sociocultural demi-regularities.

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**Midwife 4:** *The previous UCB nurses were really expert and incredibly dedicated and enthusiastic about their work, and that showed in their performance. ... . Their constant communication always kept us up to date.... Oh, God (UCB Nurse one and UCB Nurse two) they were so sweet. With them, I never felt compelled to collect; I did it because I wanted to*

*be rewarded by God by helping those cancer patients who were in desperate need of UCB units. AHH, I'm not sure why I'm so enthused, maybe because I saw some oncology patients once when (UCB Nurse one) took us on a tour of UCBBH. I remember them receiving UCB infusions from our collection.... Oh, I'm so glad I met them... Oh, God, what a pity.*

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The previous UCB team's experience as nurses before becoming UCB collectors, had seemingly allowed them to portray skills proficient in engaging the PHMD to collect UCB. It is important to clarify this point as the current UCB team, in comparison, were less well equipped to lead the interdepartmental collaboration than the previous.

The previous UCB team differed from the new team, they organized frequent informal briefings for the midwives and the rest of the PHMD team. The previous UCB team were able to increase interdepartmental communication through training and briefing sessions. Short briefings occurred daily which updated midwives on the progress of the programme, thus engaging them further with it. Subjects such as the number of collected units, short and long-term benefits and any changes were immediately relayed to the PHMD team.

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**Midwife 4:** *The previous team used to provide us with a quick updated report about the accepted and saved units or any updates in collection criteria unlike now. The new team are not initiative and not active in contact with us.*

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Alongside updates about the programme, the previous UCB team would update collection techniques and offer brief training for midwives. They would show midwives how to collect and observe their collection technique when they noticed that the rate of contamination had increased in collected units. Interestingly, the previous UCB team considered the midwives' workload and would tailor their approach to times when the workload was lighter to avoid added pressure. UCB Nurse one from the previous team also reminded the midwives of the religious rewards in participating with the programme, this reinforced the value of the programme and resulted in the midwives engaging more positively with collection of UCB.

When issues related to transportation arose (i.e., driver on sick leave or holiday), the previous UCB nurses would inform the midwives. Thus, midwives felt comfortable collecting in their

absence as they considered the prior team to be reliable, they would pick the units up before they expired.

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***Midwife 5:** ... at least, the previous UCB team was always available and so we did not notice if transportation was an issue ever.*

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The previous UCB nurses were proactive in identifying and avoiding potential problems with collection facilities. This was perhaps due to their prior work experience, as they were motivated to collect UCB units, often going beyond their remit to collect it in large quantities. Although the management of both teams remained the same, their actions differed greatly, with the actions of the previous team resulting in a higher collection rate.

In terms of mothers, the previous UCB team introduced the programme to mothers earlier, during pregnancy, to obtain consent and give the mother time to become familiar with the programme before labour. This happened in several ways; firstly, UCB Nurse one would introduce herself and the programme to mothers during their antenatal appointments in the OPD clinic or inpatients wards.

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***PHMD Manager 3:** Then she (UCB Nurse one) goes upstairs to the prenatal inpatient ward (maternity ward) to educate mothers and get their consent forms (recruit mothers for donation).*

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The previous UCB team obtained informed consent by giving mothers a copy of the consent form and contact details of the UCB team. The UCB nurse would file the signed consent forms and could access them easily if mothers did not bring their own. For registered mothers, labour at PHMD and UCBC was not halted by the need to obtain consent, consent forms were easily traceable. This freed the UCB nurse to do other tasks. In addition, mothers were told of the process during appointments or talks and were provided with brochures and information about the procedure.

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**UCB Nurse 2:** *We developed educational material to be given out to mothers so they can read the material and understand the benefits and uses of UCB stem cells.*

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Thus, mothers were able to ask for the UCB team once they were in labour. However, with the current UCB team, mothers did not have knowledge of the procedure and they were apprehensive about approaching the busy midwives regarding UCBD. This was discussed in the managerial demi-regularity.

#### 4.3.4.2. Conflicts

##### **4.3.4.2.1. Conflicts related to managerial and workplace challenges.**

The PHMD Manager was reluctant to include staff in UCBC practices, they explained, below, that this was due to perceived disrespect from the UCBBH. UCBBH had released media campaigns to advertise the programme and had omitted any inclusion of the PHMD.

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**PHMD Manager 1:** *We had enough of being ignored and unappreciated for our role in this programme... it is not sensible to give all of the credit to one party, neglecting the contributions of the others.*

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This may have been the precursor to the PHMD ordering staff to cease collection of UCB units. UCB nurses and midwives recognised that the influence that the PHMD Managers had over the midwives led to further friction between the UCB nurses and the midwives. Although PHMD Manager 3 had discreetly prohibited midwife participation, some midwives continued to collect UCB. This resulted in midwives being penalised for not obeying their superiors. Midwives who continued to collect also felt alienated and isolated as they were excluded by their peers.

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**UCB Nurse 3:** *If the manager has a disagreement with one of her staff, she may put her on the night shift for quite a while, so she does not have to see her during the daytime. Therefore, personal issues affect the work.*

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Foreign midwives were less likely to collect UCB due to fear of losing their jobs. The midwives also felt that foreign midwives who were collecting UCB voluntarily would result in collection

being made mandatory for the wider team. Therefore, to dissuade the foreign midwives from collecting UCB they isolated these midwives.

Saudi midwives had more power to go against the conformity as they did not share the same occupational fears. However, they felt that they would be ostracised for any collaborative actions. Some of the autonomy that Saudi midwives had was due to their knowledge of the contract. Foreign midwives, conversely, had been vulnerable to managerial sanctions despite the existence of the contract, as they were less protected due to their foreigner status.

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**Midwife 4:** ... we are foreigners and we do not need any extra troubles...

**Researcher:** Allow me to ask this please, why you are expecting troubles to happen when this is an agreed volunteering job between your hospital and the UCB bank?

**Midwife 4:** Things changed, and many people stopped helping in this programme ... I cannot speak proper Arabic to understand what is going around... but, I have been told by supervisor to stop the collection and I want to keep my job... I do not want trouble.

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While the previous UCB team provided continuous training and feedback for the midwives in order to maximise midwife cooperation, the current UCB team had encountered difficulties with providing the same service to midwives. UCB Nurse four described an instance where she had trained a foreign midwife on UCBC but had experienced reluctance from the midwife, resulting in no UCBC. UCB Nurse four felt that the reluctance was due to peer pressure and influences from other midwives.

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**UCB Nurse 4:** I trained her (a new midwife) but, she did not collect any UCB unit yet... [Now] She refuses to speak to me, and her co-workers have encouraged her to do so, and she ignored me; I can tell ... because their body language was so obvious to me...they conversed with her in their native tongue ... (A few seconds of silence, then a deep sigh) "I believe it was her co-workers who swayed her decision.

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#### 4.3.4.2.2. Conflicts Related to Work Ethic

Many other factors fed into the tense relationship between the two departments. Initially, when the new UCB nurse team started working with the midwives there were differences in perceived work ethic between the two UCB teams. During interviews, they accused the new UCB nurses of neglecting their duties; particularly compared with the previous UCB team.

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**Midwife 6:** *Most of the time, they wear headphones, and they cannot hear when the mother gives birth. And as you see we have a small delivery ward, and it is easy to hear the mother screams when she gets closer to give birth..., of course, they will not be able follow the progress of the labour.*

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From the midwives' perspective, the UCB nurses did not put sufficient effort in their tasks to qualify for cooperation from them. For example, the previous UCB team would ensure that supplies were sufficiently stocked and ready for collection at any point, they were able to collect at any time. However, the current UCB team would not prepare for collection beforehand and would miss out on prospective donations as a result. This was also construed by the midwives as a lack of interest in the value of the programme.

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**Midwife 3:** *I can say the previous team was more dedicated to ensuring the resources for UCBC are all available. But now, if I would like to collect (the UCB), sometimes the supplies are not available in the department. See, they did not refill the supplies, see!! This is why I do not collect the UCB units sometimes.*

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In addition to the UCB nurses missing out on prospective donors, a direct result of lack of supplies was that the midwives were not able to collect if they wished to do so. The lack of foresight of the UCB team was taken as disinterest in the programme. As a result, midwife 6 summarised her feelings regarding the UCB nurses' individual differences:

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**Midwife 6:** *They are not interested in collecting the UCB. So why should we bother helping them.*

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Individual differences in work ethic were a major grievance from the midwives' perspective. As such, the midwives' participation had decreased in comparison with their previous participation. However, these differences were not the only point of criticism, many socioeconomic and cultural issues arose from the interviews, outlined in the next segment.

#### **4.3.4.2.3. Conflicts Related to Socio-economic Differences.**

Many of the conflicts which arose in the data were pertaining to socioeconomic and cultural issues. Participants felt that there was a discernible difference in the socioeconomic and cultural backgrounds between the midwives and the UCB nurses. UCB nurses felt they were being judged by the midwives because the UCB nurses did not wear a face veil, some nurses felt that judgement of their appearance led to active dislike; inhibiting the midwife team to cooperate. UCB nurses interpreted the midwives' actions as thus,

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***UCB Nurse 4:** I would say they have a strong opinion about us because we are not wearing the veil unlike them... they do not accept us, and they do not like us, and they do not see us as Saudis.*

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The UCB nurses felt judged on their religious piety in the workplace and were thus isolated as they did not feel comfortable being with the PHMD team. The isolation felt by the UCB nurses made it difficult for them to include midwives in training, regular updates, and day to day conversation as they felt that they were constantly being judged. In addition, the current UCB team were younger than the previous team and felt they were being judged on their personal choices.

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**UCB Nurse 2:** Bear in mind, there is an age difference between the two teams, the new UCB team are of a younger generation, single with different interests such as focusing on their physical appearance.

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Conversely, midwives felt that they were being judged on their appearance, UCB nurses commented on the midwives appearing scruffy. Midwives also felt that they were being unfairly judged as UCB nurses would appear haughty and arrogant when they came to PHMD. The policies between PHMD and UCBHH differ; PHMD midwives have a high workload and have two patients at once as per policy. Therefore, essentials such as gowns and routine



sterilisation take second place in the midwives' daily tasks. However, when UCB nurses enter the wards and are working alongside the midwives, they seem visibly uncomfortable with the conditions of the ward.

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**UCB Nurse 4:** *They do not understand why we do this, if we get a gush of blood on our clothes, we look disgusted, and my safety is the first priority... Look, I understand, they are busy and sometimes, mothers arrive fully dilated and midwives will not have time to put on a gown, so they just put on gloves and perform the delivery. But this is not allowed, we do not do this at UCBBH, I mean... what about the infection control.*

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According to midwives' interviews, the body language of UCB staff was interpreted as haughtiness by the midwives. By contrast, the previous UCB team used to be mindful of their body language and how their reactions may be interpreted. They were aware that as they were UCBBH staff, the PHMD team might be conscious of the condition of their hospital. Thus, they ensured that they did not fuel any ideas of superiority towards the midwives. This shows the ways in which the experience of the previous UCB team enabled them to have soft skills to ensure interdepartmental amicability.

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**UCB Nurse 2:** *I did my best to watch my body language. Particularly, that people can easily misinterpret our body language and expressions. People see us differently in PHMD because we are UCBBH staff and they may expect us to be arrogant, because of the luxuries we have in UCBBH. Our new nurses must understand and respect these differences to avoid any misunderstanding.*

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The feeling of being judged (on both sides) seemed to be rooted in deeper issues than cultural dress and differing hospital policies. Midwives and UCB nurses raised pay disparity as a factor in their conflicts. From interviews, midwives had inferred that they were getting paid less than the UCB nurses, which in turn made them un-willing to contribute. The distribution of workload between the teams is unbalanced; midwives' workload is far higher than the UCB nurses. Ultimately, the midwives felt that as they were getting paid less and

doing more work, they should not be collecting UCB as that seemed to be UCB nurses' only task.

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**Midwife 1:** *Listen, I just do not like this attitude when they feel sorry for us 'like ... [oh, poor you ... We (UCB nurses) have less to do and better pay] ... I am sorry but this is how we feel... it's so annoying. You should not be worried about us; all you need to do is focus on your well-paying job.*

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The midwives felt that their workload should not be increased, particularly when the UCB nurses worked less hours than them. The workload of UCB nurses was not noticeable to them with the previous team, as mentioned before, whereas the midwives now felt that the UCB nurses were lazy and inactive. The resentment and jealousy felt by the midwives resulted in them refusing to participate in the programme, they viewed it as helping the UCB nurses, making it their personal battle.

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**PHMD Manager 3:** *How can they expect us to be always available for collection? or to call them for a collection? Sorry, but we're the ones who do the heavy work here, and they're paid more than we are... so let them do it.*

---

As the UCB team and PHMD midwives came from differing socio-cultural backgrounds, they had their own prejudices against each other that were perpetuated in this study. Therefore, many PHMD staff had opted not to support the UCBB programme.

#### **4.3.4.2.4. Difference in educational level and lack of soft skills**

However, the wage disparity between the two teams is ascribed to the different education levels of the teams. To qualify for midwifery a diploma is required, however, UCB nurses must obtain a nursing degree. Thus, UCB nurses felt they were unfairly criticised for the wage disparity. This difference in education level seemed to be, on the empirical level, one reason for conflict between the UCB team and the midwives. Not only did the midwives feel judged on their appearance and the way they ran the labour ward, but also because they were not as formally educated as the UCB team.

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**UCB Nurse 1:** *The PHMD staff feels inferior to the UCBBH staff because the UCBBH staff has higher education (bachelor's degrees) while the PHMD staff only has diplomas... To me, when compared to our new UCB nurses, the midwives at PHMD Hospital are more skilled and knowledgeable.*

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The midwives had more patient experience than the new UCB team, yet they felt that this experience was irrelevant when compared with the education level of the UCB nurses, despite their inexperience. Midwives had a clearer understanding of the way to approach mothers when they introduced UCBD and had other soft skills, while the current UCB team's inexperience led to mistakes. The previous UCB team recognised the midwives' skill and contribution, although the current team do not (see demi-reg two: the lack of knowledge and skills). Because of the derogatory way with which the UCB nurses treated the midwives, midwives felt a sense of inferiority and thus were unwilling to collect UCB. Midwives thought that participation in the UCB programme would only benefit the UCB team, thus did not want to help them succeed further by making the programme a success.

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**Midwife 1:** *I think we should let it be handled by them [UCBC] since they assume they know more than we do ... I do not see any reason to go through the headache of gathering the UCB units for them [UCB nurse]. Only one group (UCBBH) stands to gain from this partnership. Nothing, not even respect or appreciation, is given back to us (PHMD).*

---

This was also corroborated by the previous UCB nurses' opinion as in the quote below:

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**UCB Nurse 2:** *I believe the majority of midwives complained of being treated as inferior or unimportant by our new UCB team, which made the midwives stop interacting with them or helping them.*

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While the conflicts that were raised in interviews can inhibit a harmonious workplace, the conflicts and residual feelings of the two teams ultimately led to inaction for both parties. The UCB nurses felt misjudged, isolated, and disrespected while the midwives also felt

misjudged and disrespected on many fronts. These residual feelings led the UCB nurses to be reluctant to engage with the midwives, to offer training or to provide effective communication for the benefit of the programme. In addition, midwives were reluctant to take part in the programme, not only due to the explicit requests of their manager but also because they saw the programme's success as the success of the UCB nurses.

The conflict between UCBBH and PHMD team members was also linked to the current UCB team's lack of soft skills. A number of the UCB nurses' practice was incompatible with the PHMD's work routine and habits. For example, some informal communication practices expected by the PHMD were not met by current UCB nurses. In the quote below, a PHMD staff expressed a wish to be notified when UCB nurses are unable to attend the collecting site and described their disappointment at not being included.

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**Midwife 5:** *I used to collect [according to the UCB team schedule] from Sunday till Wednesday, if I found a good cord. But not anymore. Because sometimes they (new UCB team) just do not show up in their working days, and the blood units I collect can easily be discarded. They did not even bother to inform us that the unit can be stored at room temperature for up to 72 hours before it expires. I thought the unit would lose viability if it was not delivered to the blood bank within the first 48 hours. I only learned about this recently. They never give advance notice of their absence to the head nurse or the charge nurse. It was just a waste of my time and effort. So yeah, things have changed now.*

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This corresponded with my observation notes, I had spent approximately five months collecting data, four days a week from 8 am to 5 pm. Some of these notes revealed that the UCB nurses failed to show up for work on multiple occasions without prior notice.

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**Observation Notes:** *It is getting near to the end of the shift in the labour ward. No UCB nurse has arrived or given notice of absence. A total of four good units that met the collection criteria were just wasted. When I asked the UCB nurse 4 why she did not show up the day before, she explained*

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*that she had called in sick and only informed her direct supervisor at UCBBH as per policy.*

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The UCB nurses' lack of communication about their attendance had an impact on their collaboration with the midwives. Midwife 5, in the above quote, mentioned that her participation waned as she did not know whether the collected units would be discarded. The staff at PHMD repeatedly expressed their dissatisfaction with the lack of recognition for their efforts by the UCBBH. They expected to receive some communication when they had participated, however, they felt that the discarded units signified their lack of importance to the UCBBH.

There was little day-to-day communication between PHMD and UCBBH staff. Although the two teams occupied the same space in the hospital, it was evident that they did not coordinate with one another. Some PHMD staff were unsure of the UCB team's roles or the nature of the programme while others were surprised to learn that the UCB programme was still in place at their facility. PHMD assumed the partnership had ended since they had not seen the previous UCB nurses for some time and the new team had not introduced themselves.

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*Obstetrician 1: I thought this partnership had ended since I had not seen UCB Nurse 1 in quite some time... No, as far as I know, I never met any new nurses.*

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Mothers also seemed to have an issue with the UCB team's soft skills, particularly at the point of obtaining consent. As previously stated, consent was taken when a mother was booked in during active labour. While this has ethical implications about the sincerity of informed consent, one mother explained her experience with the recruitment practice and the way UCB nurses had approached her.

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**Mother 9:** *However, You guys [UCB nurses] rush into the labour rooms and talk to the women about donation when she's in labour! You cannot just show up like this and start talking to me about donating; actually, I have no idea who you are. You will definitely face rejection..... I do not*

*need more stress during labour sister I need to take my time to think about this programme and read about it, I want to see the fatwa [Islamic ruling] permitting this donation. More importantly, I need time to talk to husbands, and pray (Salat al-Istikhaara) before I make any decision.*

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The abrupt way in which consent was requested was a clear point of issue for mothers. As they had not been informed about UCBB, there were misconceptions about the programme. This can be seen in the next section concerning sociocultural issues connected with UCBD and UCBC.

In summary, the interpersonal conflict that arose amongst participants was rooted in issues mainly concerning communication, soft skills, and sociocultural issues. Many of the participants discussed the previous UCB team and their work ethic in comparison with the current UCB team. It would appear that many of the grievances the PHMD team spoke of, may have been caused by the lack of managerial direction faced by the current UCB team in conjunction with a lack of initiative and personal drive. In addition, the interdepartmental conflicts rooted in sociocultural differences need to be further analysed to ensure the cause is accurately identified.

## 4.4. Conclusion

This first stage of analysis described five trends. These demi-regularities were taken from the participants' perspectives and pointed to a direction for further analysis. It may seem that the barriers and facilitators are clear from participants' accounts, however, the inner structures leading to these have not been clarified. This study came with substantial data, the demi-regularities have allowed for the filtering of data, which focuses on five main trends.

Participants mostly agreed that the issue of interpersonal conflict was a major barrier for the UCB programme. Yet, this study is more concerned with the present structures leading to conflict. In the next stage of analysis, the inner structures accounting for the events seen in the demi-regularities will be uncovered.

The demi-regularities captured the empirical experiences of participants. While they did not give depth to explain how and why they occur, they provide suggestions for practice. Interdepartmental communication, education and knowledge and interpersonal skills were clearly outlined by participants and attributed to the reduction of UCBC. The issues raised

can be understood and change can be implemented based on the empirical data. On the other hand, the abduction and reproduction process will provide suggestions for other elements of the data that needs to be planned for. The causal characteristics of some mechanisms will provide tangible recommendations for UCB programme planners to implement.

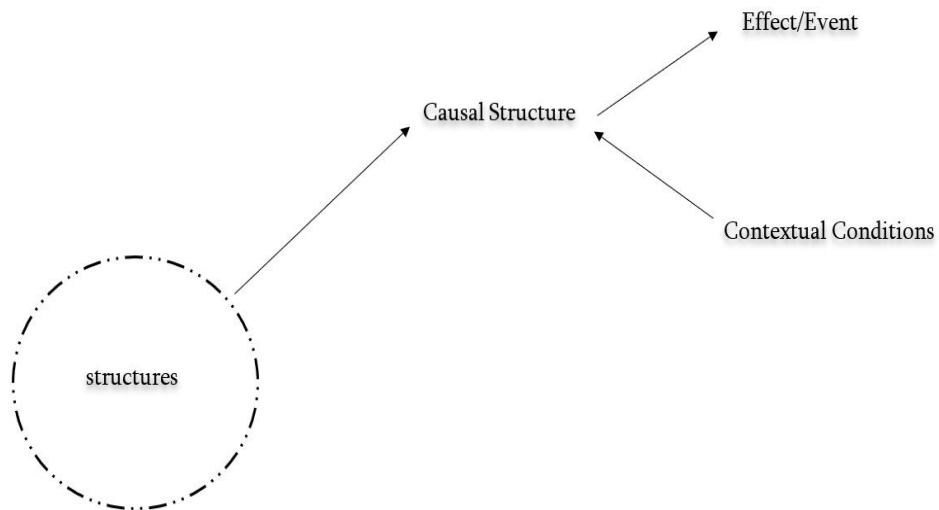
This concludes the first stage in analysis, the empirical events were laid out and the patterns were categorised into demi-regularities. The next chapter will outline the abduction and retrodution stage of analysis.

# Chapter 5. Abduction and Retroduction Analysis

## 5.1. Introduction

This chapter describes the mechanisms that resulted in the experiences of the participants. Further explanation is provided describing how the listed structures in each mechanism interact with the central causal structure. Each causal structure has the power to ignite or suppress events. The assumption here is that if causal structures are addressed, the consequences of the empirical events currently seen could be averted. Using CR allowed me to go beyond the assumptions made by the participants to reveal the causal structures that generated the observed events. By exploring these causal structures, I was able to unveil the reasons behind the fall in UCBC rate, thus achieving the aim of this research.

To understand these causal structure and mechanisms, abduction and retroduction was conducted using Sayer's (2000) mechanism components as in Figure 11. This process of abduction and retroduction is summarised in the diagram below and elaborated in the Methods Chapter (Chapter three, data analysis section):



(Drawn from Sayer, 2000)

Figure 11. (duplicate) Structure of a mechanism (Sayer 2000).

Through analysis three causal structures were highlighted as being central to many of the events that were observed. The three causal structures and their constituent mechanisms



are presented in this chapter, alongside field note observations and quotes from participants to anchor the mechanisms in empirical evidence. The three causal structures are: lack of supportive supervision and leadership, training and education, inexperience of the UCB nurses.

## 5.2. Abduction and Retroduction Findings

### 5.2.1. Causal Structure One: lack of supportive supervision and leadership.

Figure 12 below, depicts the components of the “lack of supportive supervision and leadership” mechanism. The left side of the figure shows a list of structures identified through abduction analysis. Then, through the retroduction analysis, the structures were tested and distilled further until the causal structure (at the heart of this mechanism) was finally identified. This was achieved by considering the defined contextual conditions on the lower right side of the figure, which in turn contributed to the study event shown in the figure. The explanation within this section demonstrates how the causal structure is the root of the decline in UCBB rates.

The term ‘lack of supportive supervision’ refers to lack of supervisory visits to collecting sites, open communication, enhancement of UCB nurses’ performance towards the programme’s goals and the need to handle issues that arise at the workplace before they escalate to become problematic for UCBC. It also refers to the difficulty in reaching the UCB team supervisor, when necessary, which may stifle and slow the rate of UCBC.

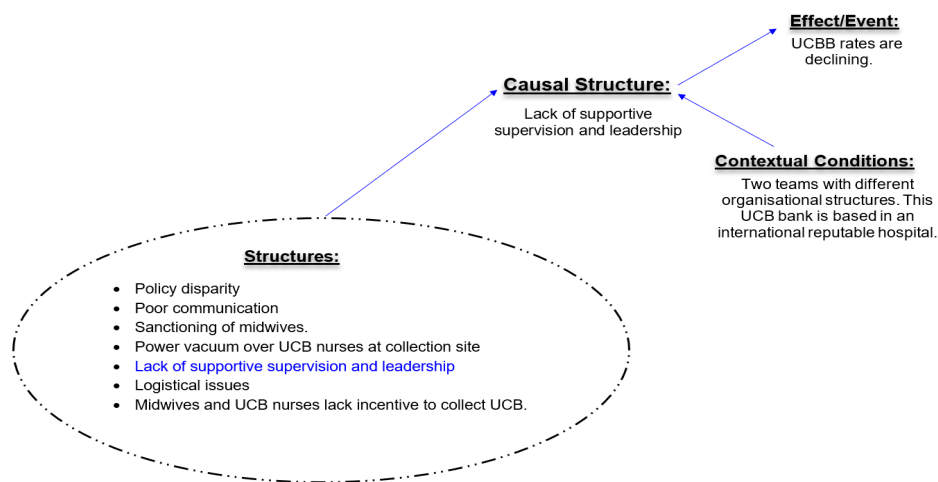


Figure 12. Lack of supportive supervision and leadership mechanism.

All of the structures listed in Figure 12 interact within the mechanism, leading to multiple barriers to UCBC, such as the interpersonal conflicts between the UCB and PHMD teams. These structures include the following:

- Differences in policies between the partnership parties regarding the practices and norms at the workplace.
- Poor communication between PHMD and UCBBH leadership
- Sanctions imposed by the PHMD leader on midwives for engaging in UCBC due to the lack of authority over UCB nurses within the delivery ward.
- Power vacuum: Leadership and control over the UCB nurses within the PHMD
- Logistic and transportation issues
- Incentives for taking part in the UCBC.

From the participant's perspective described in Chapter four, interpersonal conflict initially seemed to be the root cause for the lack of collaboration between the departments. However, the analysis revealed that the lack of supportive supervision and leadership of the UCB team had increased PHMD employees' resentment of them. This resulted in a lack of collaboration and participation in the UCBC programme by midwives. In this sense, the key causal structure of this mechanism is titled: lack of supportive supervision and leadership of the UCB team. In the explanation below, the way that structures interplay and interact with interpersonal conflict will be shown and how they are linked to the causal structure will be clarified.

#### 5.2.1.1. Structure One: Policy differences

One structure within this mechanism is the policy difference between the settings and poor communication on the part of the UCBBH, this results in the decline of UCBB rates. The differences in the policies across both parties resulted in the UCB programme itself being ill-defined. The UCB team, despite being staff of the UCBBH, worked at the PHMD and were not under the jurisdiction of the PHMD or their leadership. Both hospitals had their own systems which, at times, clashed and manifested themselves as conflicts.

PHMD policies stipulate that each midwife is responsible for all care needs of two mothers simultaneously, but at UCBBH, each midwife only has one patient at a time. Therefore, midwives at PHMD may not always prioritise some essential practices in their daily tasks, such as gown wearing and routine sterilising during emergencies. This difference in workload policy may have influenced the UCB nurses' perception of midwives' practices, causing them to feel uncomfortable while working alongside the PHMD midwives.

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**UCB nurse 4:** *They do not understand why we do this, if we get a gush of blood on our clothes, we look disgusted, and my first priority is to maintain my own safety and to keep the unit free of contamination... Look, I know, they are busy and sometimes, mothers arrive fully dilated and midwives will not have time to put on a gown, so they just put on gloves and perform the delivery. But this is not right, we do not do this at UCBBH, I mean... what about the infection control.*

---

On the other hand, the PHMD midwives felt that the UCB nurses were unfairly judging their performance as in the quote below. This difference in the workload policy has caused friction between the midwives and UCB nurses, resulting in the midwives' refusal to support the programme; this was presented in the previous Chapter (Chapter three).

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**Midwife one:** *most of the times, I have two patients to look after, and I still put some more pressure on myself to collect whenever I had time...why not...if this will benefit someone. But some days are extremely busy, and I may not collect the perfect UCB unit. And instead of appreciating my efforts, all I got was scepticism. They [UCB nurses] questioned my practice of not wearing a gown sometimes. This annoying and unfair comparison, the midwife at UCBBH must worry only about one mother at a time, whereas I have to provide full midwifery care for two expectant mothers at the same time.*

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The following excerpts also demonstrate another example of policy differences between the two hospitals with regard to blood sampling and collection. This was taken from the infection control policy documents of the two facilities.

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**PHMD policy:** *Prior to placing the butterfly needle for UCB sampling, the umbilical cord must be cleaned for 15 seconds with a large alcohol swab, applying a mild friction and twisting motion to eliminate germs effectively.*

**UCBBH policy:** *Wash the umbilical cord area with gauze 4x4 with Alcohol 70% solution followed by three alcohol swab stick followed by three*

*chlorhexidine 2% swab stick allowed it to dry repeat this step one more time, (in case of meconium stain do more frequent cord cleaning).*

---

The differences in expectations in the policy above led to further issues in the collection of UCB units by the midwives; this is demonstrated below:

***UCB nurse 4:*** *When the UCBBH lab department noticed a rise in the number of contaminated UCB units, we started monitoring the midwives while they collected UCBs... and we realised that some midwives only used one large alcohol swab and possibly one or two chlorhexidine sticks, which is inconsistent with what we actually do in this procedure. They must use three large alcohol swabs and three chlorhexidine sticks to properly disinfect the umbilical cord. Unfortunately, the midwives did not take this well; they felt that we were judging their practices, which is not true of course, and they decided to stop units collecting... And some even claimed they were doing what was required by PHMD's policy on UCB sampling. They must understand that collecting a blood sample for a lab testing is not the same as harvesting an entire UCB unit. In fact, it is more similar to a peripheral blood collecting procedure, and therefore, we must clean the cord very well prior to inserting the needle to eliminate contamination.*

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As evident from the two examples above, differences between the policies have led to operational issues in the collection of blood samples and interpersonal conflicts between the midwives and UCB nurses, this has resulted in the overall decline of UCBB rates. There is a lack of a unified approach towards the policies, oversight of the programme between the two settings and clear direction from the leadership of the UCB programme as to how these policy differences should be managed in the field. Hence the lack of supportive supervision and leadership were the key causal structures in this mechanism.

#### 5.2.1.2. Structure Two: Poor Communication

Interdepartmental communication was also another element within this mechanism. Policy documentation shows that UCBBH is responsible for keeping PHMD informed about the details of the programme. However, this was not the case due to the ambiguities in leadership and the responsibilities of supervision. This mechanism indicates that faulty

communication, coupled with other structures, suggests that the programme was only serving the UCB team. It was a sentiment seen frequently in Chapter four, particularly in the managerial demi-regularity.

As the UCBBH supervisor and manager were not often visible or accessible to both staff and leadership at PHMD, staff at PHMD felt their ideas were simply not heard and not valued. The UCBBH were clearly responsible for keeping lines of communication open with PHMD. Below are the contractual obligations:

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**Document LAB-CBB-COL- 000-Jun/2014 (contract):** *Responsibility for updating and archiving this policy rests with the department of pathology and laboratory medicine at the Public UCB Bank and the update will not be valid unless approved by the public maternity Hospital.*

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The above demonstrates that the onus is on UCBBH to convey the policy differences and programme details to the PHMD, however the quotes below demonstrate that this was not achieved.

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**PHMD manager 1:** *Despite UCBBH was sending its own nurses and technicians for UCB collection, we opened our doors and gave them the full support. We gave them our personal mobile numbers as obstetricians to contact us for any issues ... Unfortunately, they never told us how things are going in the program! They never shared any improvement plan with us... I do not understand ... how can they expect our support if they are not telling us what to do, and what is going on in this programme? ... Maybe they are satisfied with their current collection rate. How am I supposed to know? and why should I bother asking my employees to participate if this is the case?*

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The lack of clear communication on UCBBH's part and the lack of supervision of this partnership and the details of the programme led to feelings of underappreciation by the PHMD partners. This is exemplified below:

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**PHMD manager 1:** ... we had enough of being ignored and unappreciated for our role in this programme... it is not sensible to give all of the credits to one party, neglecting the contributions of the others...

**PHMD manager 2:** I will not compromise my human resources for another hospital favour. What would I get if I gave the midwives a day off to collect the UCB units? ... They lost the majority of their UCB partnership contracts; they had six partners. As far as I know, we are now their only partner; they have serious communication issues, we are a success partner, and they should treat us like as such.

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This breakdown in communication created a situation where the PHMD partners were not motivated to support the programme, leading to a decline in the UCBC rates. This was largely caused by the ambiguous leadership of the programme, which was hence considered the causal structure.

#### 5.2.1.3. Structure Three: Sanctioning of midwives.

The UCBB contract protects midwives and invites them to volunteer in the programme.

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**Document LAB-CBB-COL- 000-Jun/2014 (contract):** UCB must be collected by trained healthcare providers from UCBBH, with the assistance of competent midwives from PMHD.

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Yet midwives were informally sanctioned if they participated in UCBC, through being ostracised in informal settings or being given undesirable shift changes as a form of indirect sanctioning.

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**Midwife 4:** I have been clearly told by supervisor to stop the collection and I want to keep my job... I do not want troubles....”.

**Midwife 2:** I mean, we need something clear like an official document or a memo from PHMD to prove that we can participate in this programme with no blame. It is confusing really; we know there is a partnership contract between our hospital and the UCBB, but for some reason, our

*head nurse is indirectly instructing us to concentrate on our job and stop assisting the UCB programme.*

**Midwife 6:** *If UCBBH nurses have friendship or work relationships with a midwife, other midwives will judge her for being nice or friendly with this UCB nurse and thus that midwife will be placed in the blacklist and will never be regarded as someone to trust.... she will simply be treated as an outsider.*

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The issue here is that the PHMD midwives did not have the power to assert their right to volunteer, and they did not have a supervisor who could make assertions on their behalf. Some midwives were either unaware or unsure whether they were protected by the contract, whilst others were afraid of informal sanctioning such as undesirable shift changes as seen in the previous chapter. Thus, such a structure contributed to poor interdepartmental collaboration and ultimately affected the UCBC rate.

Although the contract documentation exists to protect the parties concerned, this protection did not translate to the parties involved. This was attributed to the lack of supervision and regulation from the UCB department, which led to miscommunication. It also led to the sense of a power vacuum, caused by the absence of UCBBH leadership in the programme, the eventual sanctioning of midwives and the fall in UCBC rates. The issue of leadership roles is expanded further in structure three below.

5.2.1.4. Structure Four: Power vacuum over UCB nurses at collection site  
UCB nurses were unsupported when conducting their tasks at collection sites. The UCB team slowed the pace of unit collection because they were sceptical of management support and felt that their well-being was not valued by their department. An example was when nurses reported two needle injuries and management failed to provide the expected support. Thus, UCB nurses decided to be more careful, tending to their injuries first rather than collecting. The lack of support also had a negative impact on their motivation to collect UCB units.

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**UCB nurse 3:** *I had lost interest in collecting the UCB after experiencing a needle injury. I was rushing to finish with a patient so that I could quickly go on to the next room and collect another unit and so on. I immediately*

*stopped everything and contacted our department, but they were extremely cold to me, showing no sympathy for my accident.*

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In another example, a UCB nurse was not supported by her supervisors when she was issued with a warning for her lateness for some shifts due to her having to report to the UCB bank.

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**UCB nurse 3:** *... I received a warning notice from human resources that I was late for multiple shifts. Because my supervisor refused to issue a memo to the human resources department explaining our late registration to the UCB bank. So, I took all the blame for this and never got any support from my supervisor.*

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There was generally a lack of supportive supervision as observed by the UCB nurses. This absence of UCB leadership was also observed by the PHMD partners:

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**PHMD manager 3:** *They are out of control, showing up to work late with full makeup and false nails while giggling and speaking loudly with my midwives and disrupting the workflow. I had several complaints about this. They do not even respect my authority and I have not seen any of their [UCB team] supervisors in years to report these behaviours. I will never allow this on my ward, I decided to impose my authority and asked my midwives to avoid unnecessary interaction with them.*

---

Since the UCB team's supervisors were rarely accessible, it was difficult to address day-to-day issues before they escalated. As seen in the previous structures, the lack of supervision and leadership on the UCB side also led to the breakdown of communication between the parties and sparked further conflict as described in the previous chapter. On the PHMD side, however, supervision and leadership were more visible but also led to the issues where the midwives were sanctioned, as shown in structure two. A power vacuum existed whereby PHMD manager 3 saw a lack of control and supervision of the UCB nurses as explained by the manager above.



Apart from asking the midwives to “avoid unnecessary interaction with” the UCB nurses, PHMD manager 3 also socially excluded the UCB nurses in other ways:

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***PHMD manager 3:** Then, the new team started socialising with some midwives in a noisy way ... they call my midwives to their lounge room for... watching movies ... or loud chatting and laughing. This distraction affected the workflow, and I received several complaints related to this attitude, so I decided to take back the lounge room, and I turned it to physicians’ room.*

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This social exclusion was also confirmed by a UCB nurse:

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***UCB nurse 2:** clearly you can see how the midwives decided to ignore the new UCB nurses...they literally refuse to deal with them.*

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The sanctioning of the midwives and social exclusion of the UCB can be seen as a form of sabotage of the programme, by PHMD manager 3, dissatisfaction with the differences in supervision and leadership between the parties and her lack of authority over the UCB nurses had implications for the UCBC rates. Hence the causal structure here is the lack of supportive supervision from the UCB team.

#### 5.2.1.5. Structure Five: Logistical issues

Logistical issues were a cause of conflict between the midwives and UCB nurses, which ultimately led to the fall in collection rates. The UCB team had to register their attendance at a different hospital, which reduced available time on the ward collecting UCB. The contractual agreement stipulates that:

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***Document LAB-CBB-COL- 000-Jun/2014 (contract):** The collection team must arrive at the Public Maternity Hospital on a daily basis, Saturday – Tuesday, from 0900 – 1600H. This schedule may be interrupted due to staff shortage or other involvement at the Public UCB Bank.*

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However, this was not the case. The UCB nurses, according to recorded field notes, would arrive at the PHMD at 10:30 am and would need to leave at 2:00pm to be able to fulfil their registration requirements. The structure here is the logistical obligations of the UCB nurses.

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**UCB nurse 3:** *We lose a lot of time in traffic; if they [UCBBH] allowed us to register our attendance at collection sites, we would save time and not be tired when we arrived at work ... I discussed this with my supervisor, she never says no, but she also never supports us when we face problems. I did it a couple times and then regretted it. Because I received a warning notice from human resources that I was late for multiple shifts. Because my supervisor refused to issue a memo to the human resources department explaining our late registration to the UCB bank. So, I took all the blame for this and never got any support from my supervisor. I was the scapegoat.*

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The field note below shows that logistical issues led to the entire UCB team being absent from PHMD several times during the data collection period, and therefore unable to collect UCB units.

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**Observation note:** *it is getting near to the end of the shift in the labour ward. No UCB nurse has arrived or given notice of absence. A total of four good units that met the collection criteria were just wasted. When I asked the UCB nurse why she did not show up the day before, she explained that the driver did not arrive for work and so we did not have transportation to come in to work.*

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The absence of the UCB nurses was interpreted as a poor work ethic when their absence was not notified or explained. According to midwife 5:

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**Midwife 5:** *Sometimes they [current UCB team] just do not show up in their working days, and the unit I collected can be easily discarded... They*

*never give advance notice of their absence to the head nurse or the charge nurse. It was just a waste of my time and effort.*

---

Outwardly, the UCB team appeared to arrive at the PHMD late, however they were completing tasks stipulated by ineffective management (I.e., lack of supportive supervision). Some PHMD staff noticed this as well, as evidenced by the following quote.

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**Midwife 3:** *I believe it is not always their [UCB nurses] fault that they do not show up at the site. No, there are transportation issues, for example if their driver is on holiday or calls in sick, they are unable to attend. However, they do not even let us know until we see them next.*

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The midwives interpreted the UCB team's hours as an indication of their work ethic. Both the feelings of resentment and the reduced hours available for UCBC are the effect of logistical issues and lack of communication from the UCB nurses. This was in turn caused by the lack of supportive supervision of the UCB nurses. This interaction hence demonstrates that the lack of supportive supervision is the causal structure here since, through the logistical issues, it reduced the hours for UCB nurses to collect units and fuelled further clashes between the midwives and UCB nurses, ultimately affecting the rate of UCBC.

#### 5.2.1.6. Structure Six: Midwives and UCB nurses lack incentive to collect UCB

One of the main complaints of the PHMD midwives was that there was a lack of incentives for the voluntary collection of UCB units (Chapter four, demi-regularity four). The PHMD midwives were initially convinced that the additional workload of collecting UCB would be incentivised. In KSA, continuous medical education (CME) hours are essential for healthcare professionals to accumulate to renew their caregiver license every 3-5 years. In Chapter four the midwives spoke of wishing to have CME hours in exchange for UCBC, this would help them further their professional growth. The PHMD had relied on the reputation of their partners (UCBBH) and expected to benefit from the relationship in some way. The PHMD midwives were disappointed when the incentives were not provided, they felt it was indicative of their lack of value to the programme and their career prospects. As diploma qualification holders they hoped that there would be mutual benefits to the UCB programme,

the PHMD midwives could be trained at a tertiary, well established UCBBH, and the UCB programme would benefit from more UCBC.

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**PHMD manager 1:** *I believe if they [UCBBH] provide us CME-accredited training courses or honour titles like UCB collector or specialist, the midwives will feel valued and driven to collect UCB units. Basically, this is how we encourage them to take part in the breastfeeding programme.*

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The data here implied that there was a desire to move up the career ladder. The midwives' diploma-level accreditation had limited their career prospects. In comparison, the UCB nurses were educated to degree-level, to midwives, however, the workload and the importance of the task were not indicative of UCB team's professional status.

On the other hand, the UCB nurses themselves felt that they were just lab technicians, they felt despondent about the programme and its ability to further their prospects.

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**UCB nurse 2:** *It's [UCBC] a straightforward procedure, and it can perfectly be handled by a lab technician. Assigning a nurse to this role will limit her experience and career options. They should pay more attention to our professional development.*

---

UCB nurses also wanted to move forward in their own professions. However, the lack of opportunities for professional development as nurses within the lab department inhibited their passion, and they became less invested in the success of the programme. This was particularly the case when it was paired with exclusion from departmental meetings, the UCB nurses preferred to do the minimum necessary for their roles.

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**UCB nurse 4:** *I'm fed up with this stagnation ... and then what? I really need to move up the ranks and get a higher position. Why should I bother to improve things?... a little bit of inspiration or hope would not do any harm.*

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However, the salaries of UCB nurses were higher than those of the midwives. In addition, their accreditation provided them a number of professional opportunities as nurses. Midwives could not be promoted beyond midwifery positions, however, as nurses the UCB team could obtain promotion beyond the UCB programme, and were offered more opportunities in nursing field if this was of interest to them.

The programme should have provided professional benefits to both PHMD midwives and the UCB nurses. As it stood, the programme did not provide that and resulted in reduced midwife participation and despondency from the UCB nurses. There is a lack of incentives for the PHMD staff and UCB nurses.

The ideas of aspiration and professional outlook were complicated. However, at the centre of these complex and interwoven structures was the lack of supportive supervision to incentivise participation in the programme from both the UCB nurses and midwives.

Although the previous UCB team had no clear physical rewards for midwives who collected UCB, the previous UCB team had been able to encourage participation by providing details of the successful processing of collected UCB units and touring the UCBBH to meet the recipients of the UCBD.

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**Midwife 4:** *With them, I felt compelled to collect; I did it because I wanted to be rewarded by God by helping those cancer patients who were in desperate need of UCB units. AHH, I'm not sure why I'm so enthused, maybe because I saw some oncology patients once when (UCB nurse one) took us on a tour of UCBBH. I remember them receiving UCB infusions from our collection.... Oh, I'm so glad I met them.*

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The collection of UCB is currently poorly incentivised, leading to the lacklustre efforts of the midwives and UCB team. The previous UCB team had shown how supportive supervision and leadership could motivate more proactive participation in the programme. Thus, it demonstrates how the causal structure (the lack of supportive supervision) has contributed to the overall decline in UCBC.

To conclude, although all the structures contributed to the overall phenomena of reduction in UCB collected, lack of supportive supervision and leadership were seen as the main causes

of the described structures. Therefore, this causal structure lies in the heart of this mechanism and has generative power to cause the decline in UCBD and collection rates.

The added layer of each mechanism is the contextual conditions within which each mechanism operates. While extracting structures and their encompassing mechanism I asked myself what are the contextual conditions that allow the mechanism to continue? and how does it happen? In the above mechanism there were two defining, contextual factors. Firstly, the UCB programme relied upon two distinctly unique organisations; the UCB team and the PHMD, both of which had differing organisational structures and regulations. Secondly, the UCBB was controlled and housed externally to the PHMD and therefore was seen as owned by the reputable, tertiary, research hospital. Without these conditions, structures such as the policy differences would have had less far-reaching effects than it currently has. Without the issue of communication between two distinct organisations, some of the structures such as the power vacuum that existed, may have had less of an effect on the overall UCB collection rate. The above mechanism was therefore generated due to the lack of supportive supervision and leadership (causal structure) and was allowed to thrive due to these contextual conditions.

### 5.2.2. Causal Structure Two: UCB programme education and training.

The lack of a UCB training programme was a long-running issue amongst participant groups, either generally or for specific aspects of UCB-based interventions. The analysis found two mechanisms related to this theme, one around parents' education and training where parents lacked the required knowledge to donate the UCB units; the other was in relation to the UCB nurses' lack of regular training. The current UCB nurses lacked the necessary knowledge to convey information about the programme to other participant groups. The two subsequent sections (A and B) explain how these two causal structures accounted for many of the responses seen in Chapter four. It will also show how they interplay with the other relevant structures and contributed to the drop in UCBD and UCBC rates.

#### 5.2.2.1. Causal structure 2A: Parents' education and UCB programme training

The mechanism below concerns many of the misconceptions around UCB that were revealed during interviews. Figure 13 demonstrates the mechanism by which the parents' education and training emerged as a causal structure in relation to other relevant structures, contextual conditions and the empirical event.

During interviews many mothers expressed their fear of the consequences of donating UCB, this was due to cultural factors or misconceptions that UCBC may be harmful to the mother or her child. Some mothers were fearful of cultural repercussions such as displeasing their husbands or family members, there were also fears in relation to black magic and malicious intent from the collected UCB unit. Additionally, some fears were health related. The structures are the parent's trust in the UCB nurse's knowledge, consent acquisition process, timing of consent and education of parents, and parents' education background and cultural influences. These structures suggest that the parent's education and training is the causal structure, and this is further explored in the sections below.

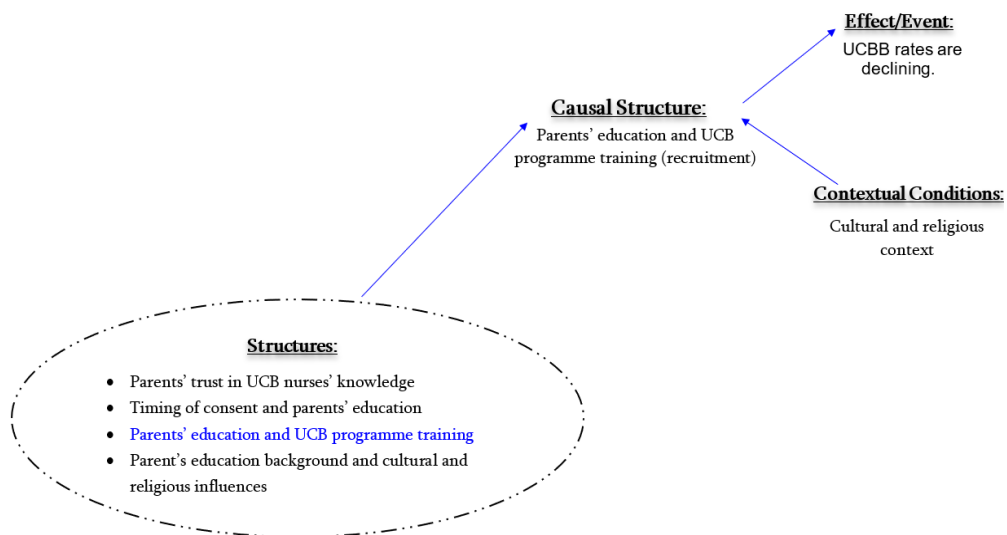


Figure 13. Parents' education and UCB programme training.

#### 5.2.2.1.1. Structure One: Parents' trust in UCB nurses' knowledge

A key issue that emerged was the parents' lack of trust in UCB nurses' knowledge and how the nurses had been unsuccessful at allaying their concerns about donation. Hence, they refused to donate their UCB units. The parents' fears over donating implied a distrust of UCB nurses' authority and the legitimacy of the programme itself (see Chapter four, demiregularity three). The authority of the UCB nurses was in question for some parents, they did not have confidence in the nurses' qualifications and expressed a preference for doctors to explain the UCB programme details.

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**Mother 7:** I'd rather have the doctor to explain the donation options to me since, in my opinion, he/she should know better than the nurse...

more educated, more experienced. Otherwise, I could feel doubtful and uncomfortable.

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The programme did not seem legitimate to mothers whose first interaction with UCBD was through an unfamiliar nurse. The role of the UCB nurse was to convey the programme's message to the parents, yet due to misinterpretation parents were fearful of the risks of donation for themselves or their child. Midwife 1 also noted that mothers need to know more to develop trust in the UCB nurses:

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**Midwife 1:** *Mothers need to know more information to trust you. If you know enough, you can approach mothers better... you will be more confident.*

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Parents' mistrust of the UCB nurses stemmed from their lack of understanding about the role of the UCB nurses. This could have been due to stereotypes perpetuated by social perspectives of nurses in general and the superiority of doctors in healthcare settings. An appropriate introduction to the nurses, education on UCB nurses, their role in the UCB programme, and details and processes of UCBD would have clarified matters for parents and helped to build their trust in UCB nurses. Hence the parent's education and training emerged as a causal structure in this mechanism.

#### **5.2.2.1.2. Structure Two: Timing of Consent and Parents' Education**

The timing of the introduction to the programme for mothers and of obtaining consent was inappropriate. This resulted in the parents questioning the legitimacy of the programme. Mothers were approached and introduced to the UCB programme during active labour, this was inappropriate for providing quality information.

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**Observation note:** *A mother is in active labour, with contractions occurring every 5 to 8 minutes and the cervix dilation measuring 6 cm. The UCB nurse walked toward the mother and introduced herself and started to talk about the UCB programme and how she could participate and help cancer patients if she chose to donate the UCB. The information provided was insufficient for anyone to make a well-informed decision.*



*The mother's surprise and suspicion could be felt. "I'm sorry, I do not know who you are; could you please call the midwife?". The midwife calmed the mother and confirmed that this is a hospital-approved programme. The mother was upset that the doctor or midwife had not informed her about this programme sooner. She then asked the UCB nurse to leave because she is now in intense pain and unable to talk.*

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This form of approaching mothers was a clear barrier to donation. Also, one mother shared her story of being recruited by UCB nurses, highlighting ethical concerns regarding the validity of informed consent.

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**Mother 9:** *However, you guys' [UCB nurses] rush into the labour rooms and talk to the women about donation when she's in labour! You cannot just show up like this and start talking to me about donating; actually, I have no idea who you are. You will definitely face rejection... I do not need more stress during labour sister. I need to take my time to think about this programme and read about it, I want to see the fatwa [Islamic ruling] permitting this donation... before I make any decision.*

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The mother above noted that the timing in which consent is requested, and also education about the programme, was poor, it caused added stress during labour and ultimately consent was not given. Additionally, the contract documentation does not clearly state the timing of obtaining consent.

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**Document LAB-CBB-COL- 000-Jun/2014 (contract):** *Whenever possible, informed consent is obtained prior to the onset of labour. Informed consent shall be obtained and documented while the mother is able to concentrate on the information and is not distracted by aspects of labour.*

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The current UCB team practice of obtaining consent during labour goes against the contract. Due to the nature of labour, it may be difficult to specify an appropriate time point for requesting consent, but the intention is that women are not approached once in severe pain.

Mothers may also have been misinformed about the programme by the UCB nurses' poor training. This was noted by UCB nurse 2 who was part of the old UCB team in her observation of the current UCB team.

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**UCB nurse 2:** *Sometimes they give mothers false information, they give false impressions and promises... They need serious training, and I do not think they are ready for this task. They are newly graduated with no previous experience, at least they need regular training on how to approach mothers for donating.*

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The parents' need for information was intertwined with the UCB nurses' need for education. In the quote below Midwife 1 noted that UCB nurses lacked knowledge in approaching and educating mothers on donation.

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**Midwife 1:** *The way they [UCB nurses] approach mothers to donate is not sufficient, they need to learn more about the UCBB... why it is important, what for.*

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The partnership contract indicated the UCB team's responsibility to provide UCB-related educational material to pregnant mothers.

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**Document LAB-CBB-COL- 000-Jun/2014 (contract):** *The PHMD should allow the UCB team to fulfil their responsibility of distributing the advertising and proper education material for the UCBD Programme.*

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Field observations and participant interviews revealed that the UCB team were not meeting the contract terms, they failed to distribute materials to pregnant women during the recruitment process. Conversely, when information was provided and consent was sought at the appropriate times, mothers were more eager to participate in the programme. Below, a PHMD manager described how one of the previous team members of the UCB department educated mothers on the programme early and therefore developed the trust of parents regarding the programme.

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**PHMD manager 3:** *Whenever the labour ward was not busy, she [UCB nurse 1] ran to the OPD department and the prenatal inpatient ward to recruit donors and record the information of the pregnant mothers who had already signed the informed consent to donate the UCB and were due to give birth soon. ... Mothers especially were eager to help out, as they have a clear understanding of the importance of this programme. Some of them even bring up the fact that they signed the consent for donation in the OPD.*

---

The timing of the recruitment was poorly chosen, and insufficient time was afforded for the mothers to read and understand the material and information provided. This resulted in scepticism about the programme and refusal to donate. Hence educating mothers about the programme is the causal structure here.

#### **5.2.2.1.3. Structure Three: Parent's educational background and cultural and religious influences**

Two mothers had achieved education degrees, they may have had access to UCB information from credible sources such as educational institutions. Thus, they were less sensitive to cultural and religious misconceptions regarding UCBD.

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**Mother 1:** *I studied sociology in university, but I heard about stem cells in a class called "general health," which was an elective class. It was interesting, but when I decided to donate my UCB unit, I found a lot of UCBB information on social media. I also tweeted some of my queries to obstetricians, who responded well.*

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This was congruent with the PHMD manager's perspective, as stated in the quotation below. Many female patients at PHMD are under considerable pressure from male relatives (fathers, husbands, or brothers) to abandon their education in favour of caring for children and the household.

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**PHMD manager 2:** *Most of women in this area are not highly educated. Either they are illiterate or have intermediate education or if lucky have high school level (grade12) ... Many of them were not permitted to further*

*their schooling, since they married at an early age... So, they may never learn about stem cells or their advantages, which they could have learned from school curricula. Unlike UCBBH, where most of their patients are highly educated and more open-minded.*

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In this study only two mothers out of nine had donated UCB units previously, they were all university graduates. Several participants across all the participant groups stressed the need to educate mothers on both general UCB knowledge (e.g., stem cell benefits) and that of the UCB programme (e.g., donation criteria and market demands). Pregnant women may benefit from having UCB education incorporated into routine prenatal care. It may also help to dispel myths and reduce their fears of social consequences (e.g., divorce) and cultural superstitions (Chapter four-demi-reg. three).

In the absence of proper training and education on the UCBB, sociocultural issues such as patriarchy, fear of black magic or mixing lineages, could thrive and became the main empirical barriers.

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**Antenatal nurse 2:** *Once in the labour room, I remember a mother giving her early permission for UCBD. The UCB nurse visited her the following day, when she was moved to the post-partum department, to confirm the consent, get more information from the mother, and collect some peripheral blood samples. I was surprised to learn that the mother had changed her mind after a phone call with the husband. The mother refused to continue the donation process. I was curious as to why she had changed her mind after giving consent to donate, so I immediately asked her. She said "my husband refused the donation. It just does not sound right. She just stepped into my room after I gave birth and demanded my blood. Is not that strange?!! and she got my all-personal information. I'm afraid that someone who knows who I am will use my blood for black magic to hurt me or my child.*

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Similarly, during data collection one mother asked the midwife for additional details about the UCB programme. This occurred because the UCB nurse had failed to provide the mother with sufficient information to enable her to make an informed decision about the UCBD.

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**Observation note:** *The mother signed the consent form when the unit harvest was completed. No educational materials or Islamic rulings on UCBD were given to the mother. After some time had passed, she called the midwife and began asking several questions about the UCB programme, as she was curious to learn more about it... and whether there was an Islamic ruling permitting this.*

---

In Chapter four patriarchy and religious beliefs were given as reasons why mothers refused UCBD. Suspicions of black magic were embedded in the cultural and religious beliefs of these mothers, some of these fears were due to the manner in which parents were informed about UCBD.

Several participants advocated for including fathers in the UCB education programme and consent taking to avoid unnecessary conflict. This also aligned with the mothers' view that the husbands' refusal of donation was driven by familial duty and a desire to protect them from any potential harm.

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**Mother 5:** *It is not worth the consequences... Why do not you just involve the fathers? Just tell them about the programme... and save yourself the troubles. Believe me, as soon as they are [fathers] informed, they will not reject the donation because it is a noble deed, and the man's main concerns are protecting his family and feeling respected rather than disregarded.*

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Culture and religious beliefs are clearly structures in this mechanism, however, the analysis found that culture was not the primary reason for the decline in donation rates, rather, a lack of thoughtful and time-sensitive methods of obtaining informed consent and educating mothers. Due to Saudi's patriarchal society, it would be beneficial if both parents were informed about the UCB programme. Therefore, the key causal structure in this mechanism was the parents' background and their understanding of the programme, becoming a barrier to the parents' participation. Should this causal structure be reversed, through regularly educating mothers before labour, the other structures existing in Figure 13 would become dormant. The causal structure here interacted with the earlier-discussed structures to

increase mothers' suspicion of the UCBC procedure, and with it structures concerning cultural fears had become more prominent. Ultimately, the heightened perceived risk of donating had led to mothers refusing to donate, and therefore impacting upon UCBD rates.

In the above-describe mechanism three structures were highlighted: the parent's trust in the UCB nurse's knowledge, timing of consent, parents' educational background and cultural and religious influences. In all structures, the training and education of parents was the causal structure that contributed to the declining rate of UCB. Parents were opposed to donation mainly due to the way they had been informed about the programme, most cited cultural and religious reasons. Thus, although culture played a significant part in donation refusal, it was not deemed as the key barrier to the UCBC. Contextual conditions of this mechanism were the cultural and religious context underpinning this study setting. The healthcare team and the parents were all Muslim and female, therefore were bound by the written and unwritten religious and tribal rules. In this mechanism issues such as fear of marital repercussions, such as divorce, are significant for a woman in KSA more so than in cultural settings. Furthermore, misinformation due to the timing and process of seeking consent from mothers led to them being fearful of repercussions, these were rooted in their beliefs. Thus, the contextual conditions in which the mechanism was allowed to continue were due to the belief systems of the participants.

#### 5.2.2.2. Causal structure 2B: UCB nurses' training:

Figure 14 depicts the mechanism's central causal structure: UCB nurses' education and training in relation to the other mechanism elements (relevant structures, contextual conditions and empirical event). In Chapter four the UCB nurses reported (demi-regularity two) that they were not trained on UCB policy and procedure and were not updated on any administrative news of the programme. In addition, there was little training available to the UCB team regarding approaching donor mothers for recruitment. Training was not provided to inform UCB nurses of the wider aims of the programme, nor the recipients of the donated UCB units. In this study, participants' definitions of training included information on the programme's aim, partners and administrative information. Training also included updates and observations on procedural practices and recruitment process.

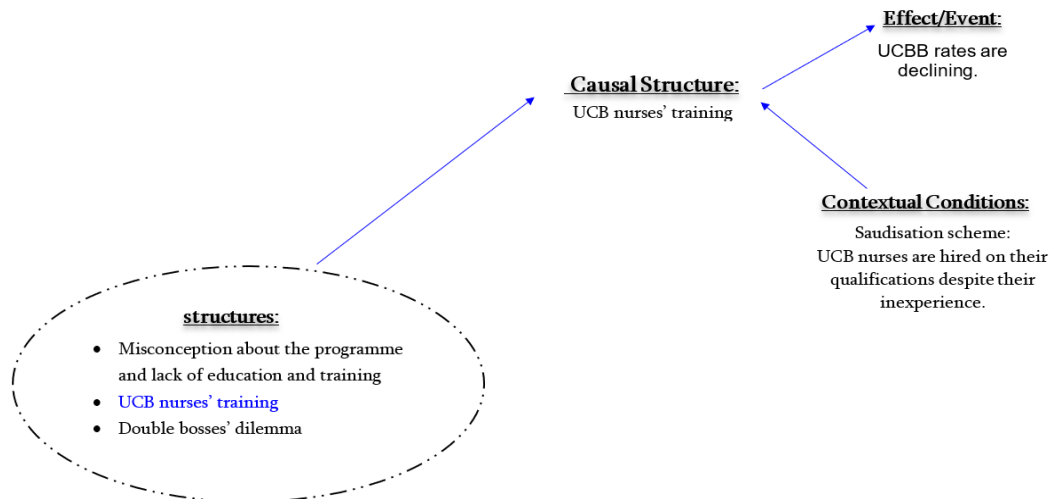


Figure 14. UCB nurses' training mechanism.

#### 5.2.2.2.1. Structure One: Misconception about the programme and lack of education and training.

From my own nursing experience, I expected some practices to occur as standard. However, I have observed that some of these expected practices, such as regular team meetings or briefings, did not occur, implying that the staff were not updated regularly.

UCB nurses mentioned that they were unaware of many elements of the programme. For example, they did not know the wider uses of UCB in healthcare beyond cancer treatment.

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*UCB nurse 3: I feel like I need to learn more about the wider uses and risks of UCB transplant. I would not know where to begin even if I wanted to. All I know is that it is used to treat some haematology disorders, mainly thalassemia and leukemia.*

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On the other hand, the UCB nurses were also responsible for the training and education of the PHMD partners on the programme:

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*Document LAB-CBB-COL- 000-Jun/2014 (contract): UCBBH UCBC team are the ones responsible for the continuous education for PHMD staff regarding the UCBC procedure and process.*

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As the UCB nurses were poorly educated on the programme themselves, this led to misconceptions about the programme by the midwives:

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**Midwife 5:** *The blood units I collect can easily discarded. They [UCB team] did not even bother to inform us that the unit can be stored at room temperature for up to 72 hours before it expired. I thought the unit would lose viability if it was not delivered to the blood bank within the first 48 hours. I only learned out about this recently...It was just a waste for my time and effort. So yeah, things have changed now.*

---

The quote above shows the PHMD midwife thought that UCB units had to be discarded after 24 hours, when in fact they could remain unrefrigerated for up to 72 hours.

Furthermore, the UCB nurses were also not trained in the process of obtaining consent for UCBD from mothers and had misinformed mothers about the programme, as explained in previous causal structure 2a (structure 2). This seemed to have reduced the likelihood of collecting more quantities of UCB units.

The key causal structure was that UCB nurses were not sufficiently trained and were unable to suitably inform other participant groups on the UCB programme, this had a distinct impact on all participant groups.

#### **5.2.2.2. Structure Two: Double Bosses Dilemma**

UCB nurses felt they were located between two departments, laboratory and nursing, and were not clear about their roles. This structure was named the double bosses dilemma. The nurses were answerable to both departments and often had to switch between the two.

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**UCB nurse 4:** *The most confusing part is that our annual performance appraisal is conducted by the nursing department. We struggle to ask the question of who is our boss? What shall we do in case of conflicts? We do not have the support of any of these managements.*

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As they were answerable to both the laboratory and the nursing departments their training opportunities were often overlooked and underdeveloped. The nurses also did not know where to turn when they required extra training practice in collecting UCB.



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**UCB nurse 3:** ... definitely, I would take courses related to the UCBC and stem cells. We were promised when we first hired for this position, but nothing happened. They said they would take us to Barcelona (sarcastic tone) for the international UCB conference, but nothing happened. They never sent us either international or national courses. All the updates and courses are limited to our management and the lab staff, and we are not updated about the banking progress.

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When questioned about whether the participant had raised the issue with the nursing department specifically about her training needs, she stated that the nursing department was not interested in their development as it was outside their remit.

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**UCB nurse 3:** The nursing department itself was not bothered about our training, to them, yes, we are nurses but not under their authority. This is weird, to be honest; the nursing department is in charge of our yearly assessment, but they have no idea about our needs or professional development.

---

This related to the lack of training and education causal structure, there was confusion as to which subject they should train in. Some nurses had aspirations within nursing but did not know how to progress on that route. Others felt that their position was just as laboratory specialists and were despondent about their future.

The double bosses' dilemma structure interacted with the causal structure alongside the nurses' ability to see longevity within the programme. Their dilemma was that they were caught between two departments with neither department taking responsibility for their development, this led to stagnation and a feeling of despondency. As a result, the UCB nurses did not feel they were valued by their leaders, they felt that they were not given autonomy in decisions on training.

To conclude this mechanism, the causal structure which had generative power to reduce the UCBC rate was the training and education of the UCB nurses. Due to their lack of training, the structures described above became significant obstacles for the programme. The UCB nurses were not provided with the necessary training to collect UCB units at a satisfactory level, and

this led to a reduced rate. For this mechanism, the contextual conditions that were outlined was the Saudisation scheme. The previous UCB team, who were particularly successful at collecting UCB units, were not replaced when they left due to the increased demand for health departments to rely on Saudi citizens. The scheme, although significant to the mechanism, is not the reason for the fall in collection rates but it formed an environment in which the mechanism could thrive.

### 5.2.3. Causal Structure three: Inexperience of the UCB nurses

The current UCB team was inexperienced when they became key members of the UCBC process. Figure 15 shows the structures, causal structure and Saudisation as the contextual condition of this mechanism. In this mechanism, cultural differences and the lack of soft skills appear to be a consequence of the inexperience of the UCB nurses, and this has contributed to the conflict between the UCB nurses and PHMD midwives and the eventual decline in UCBC rates.

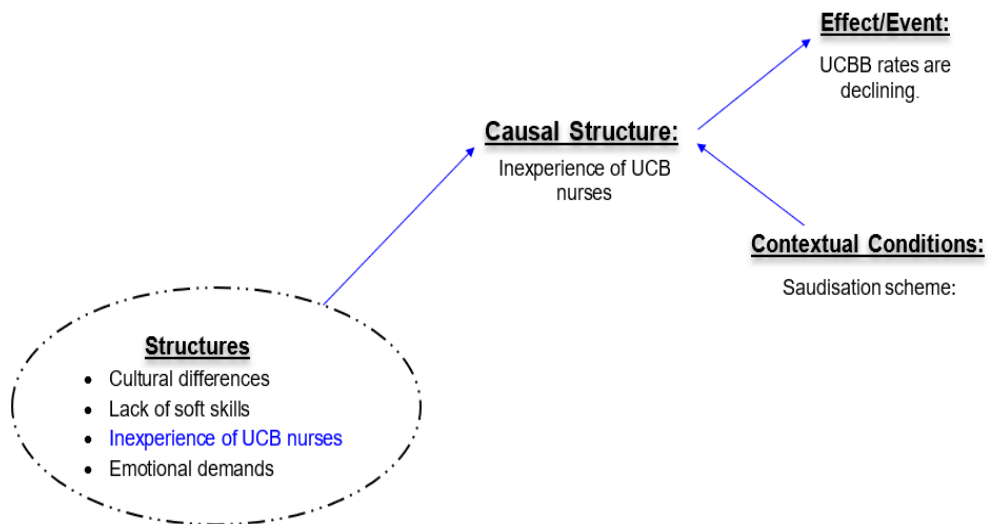


Figure 15. Inexperience of UCB nurses' mechanism.

#### 5.2.3.1. Structure One: Cultural differences

PHMD manager 3, during interviews, raised issues concerning identity and religion when discussing some of the conflicts between the departments.

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**PHMD manager 3:** *They do not seem professional to me. I really do not get it! How could a professional nurse show up to work with painted nails*

*and without the proper hijab? ... it just does not sound right to me. Especially because they are Saudi and Muslim women, and they are well aware of this. They should not do anything that might undermine this.*

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The UCB nurse in the below quote was under the impression that midwives were passing judgment on them based on their appearance (not wearing facial veil).

**UCB nurse 4:** *would say they have a strong opinion about us because we are not wearing the veil unlike them... they do not accept us, and they do not like us, and they do not see us as Saudis... They were never nice to me or my other colleague UCB nurse 5. But UCB nurse 3 is given preferential treatment compared to us... they like her, and they help, and they may collect some units for her, but not us.... I think because we are not alike, we do not wear veils ... There is no harmony between us.*

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The facial veil is a symbol of the Saudi woman's identity and the UCB nurses, according to midwives, were not acting in accordance with this practice. The differences in Islamic perceptions, however, were not deemed to be causal, rather the youth and inexperience of the UCB department was seen as the causality of some of the interdepartmental rifts.

The interpersonal relationships of staff in each department were tense, and as such it was observed that each party was unwilling to aid those who opposed them. However, UCB nurse 3, from the current team, showed more productive interpersonal relationships with the midwives and was able to engage the midwives and persuade them to participate. This was in part due to the fact that UCB nurse 3 was able to relate to the belief systems that were present for the midwives, she also shared similar identities with them.

**Midwife 6:** *UCB nurse one was dedicated to her work and kept us informed of any changes, and I genuinely liked sharing this experience [UCBC] with her... To be honest, I can think of only one UCB nurse on the current team who maybe resembles the previous UCB team, and that is UCB nurse 3... I mean, she is aware of her responsibilities and available to carry them, she does not expect me or need me to call her or help her to carry out these duties... she makes several ward rounds throughout the*

*day, so she is usually aware of those available potential donors in the ward, and thus recruits them ahead of time, and more importantly, she prepares the collection set ahead of time before the mother give birth. She is usually around us and ready to collect the units.*

**Researcher:** *So, you have mentioned that UCB nurse 3 is distinct and not like the other two UCB nurses in terms of dedication. Can you think of any other differences, I mean, how else do they differ?*

**Midwife 6:** *... UCB nurse 3 is humbler and more respectful. I have never noticed her try to deny who is she in the first place... She is conservative, does not overdo her appearance at the workplace or wear makeup like others, I have never felt her try to deny who she is in the first place... She has never abandoned her veil.*

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All the participants in this study were Muslim, and therefore shared the same basic beliefs. However, UCB nurse 3 was able to relate more effectively with the PHMD midwives because of her adherence to the traditional practices. Thus, even though she belonged to a different organisation and had the same professional tasks as the rest of the current UCB team, the midwives were able to morph their preconceived notions of her and establish a more productive working relationship. As the midwives were able to identify with UCB nurse 3, they supported her work by calling her when a patient was able to donate UCB. This interaction indicated that PHMD midwives were nurturing their professional relationship with UCB nurse 3. UCB nurse 3 also reportedly had more experience than the rest of the current UCB team. Therefore, she was perhaps able to communicate more effectively with the PHMD midwives, as did the previous UCB team (UCB nurse 1 and 2).

Additionally, the previous UCB team shared many of the same identities and beliefs that the midwives held. There was a consensus of conservative Islamic tendencies, such as wearing the veil and little makeup, whereas two of the three current UCB nurses seemed to hold more liberal views. This enabled the midwives to have a positive relationship with the previous UCB team, as well as UCB nurse 3 from the current team, based on identities.

The constant reminder of UCBD and UCBC as a philanthropic act, by the previous UCB team, appealed to the cultural alignment and religious beliefs of the PHMD midwives. This

motivated the midwives to participate more actively in the programme. However, the current UCB team were not able to do so as they had different cultural practices that were thought to be more liberal than that of the PHMD midwives. As such, this created a rift between the midwives and themselves.

UCB nurse 1 attributes this difference between the current and previous UCB teams to the difference in their experiences as nurses:

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**UCB nurse 1:** *I believe that having freshly graduated nurses in the UCB programme is unfair for these nurses. This is the difference between us and the current UCB team. Being an expert in the field of nursing developed and enhanced our nursing skills as well as personal skills such as communication and critical thinking skills, respect the differences between us and PHMD staff in terms of limited resources, and especially that the majority of the PHMD staff are conservative and religious people?*

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The lack of cultural sensitivity in the way the new UCB team carried themselves in the workplace was seen to be indicative of their inexperience in nursing in general. Hence, the inexperience of the UCB team was seen to be a causal structure which interacted with the structure on cultural differences.

#### 5.2.3.2. Structure Two: Lack of soft skills

As explored in the previous causal structure the nurses' process of obtaining informed consent was not helpful in encouraging mothers to donate. In this mechanism, however, this can be seen as a lack of soft skills in areas such as communication. This structure also interacted with the lack of training provided for UCB nurses as explored in the previous causal structure.

More importantly, the lack of soft skills resulted in friction between the UCB team and the PHMD partners, it weakened the collaboration. In the quote below, the PHMD manager describes how the poor communication skills of the UCB team led to some frustration about the partnership.

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**PHMD manager 1:** *Sometimes, the nurses just do not show up to the labour ward and they do not inform the head nurse of their intentions.*

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*How can they expect our support if they are not telling us what to do, and what is going on in this programme? Maybe they are satisfied with their current collection rate. How am I supposed to know?*

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Additionally, the quote below is from a midwife who also observed a lack of other soft skills such as initiative and proactivity in the UCB nurses when it came to collection.

**Midwife 2:** *They (UCB nurses) should not wait for the midwives to call for them to perform their duties. And as soon as they arrive, they should go through the wards and determine which cases are in active labour to be ready and prepared for collection. I am sorry, but they should not wait until after the mother gives birth to prepare for collection, expecting me to call them... That's not my job.*

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Compared with the previous UCB team, Midwife 4 noted a difference in communication skills:

**Midwife 4:** *The previous nurses were really expert, and incredibly dedicated, and enthusiastic about their work, and that showed in their performance. ... . Their constant communication always kept us up to date.*

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Communication skills of the current UCB team is important within the collaboration between UCBBH and PHMD. Expectations of behaviour and standards were a source of conflict that could have been avoided with better communication strategies such as in the example above. The previous UCB team engaged with the PHMD partners more proactively by keeping them up to date on the programme, this resulted in them being motivated to support the programme. The lack of communication skills had far-reaching effects where conflict emerged due to differences in policies, misunderstanding and lack of information about the programme as well as cultural differences. While these were issues in themselves, the lack of communication further exacerbated the friction between the two parties.

The previous team were generally more experienced in the nursing field, particularly within oncology departments and thus, had a stronger set of soft skills that might have made the programme more successful.

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**UCB Team Supervisor:** *I am not trying here to complain or compare the members of my team; that would be unfair. But UCB nurse one and two, were delivering about 8 to 10 units per day to the lab department... (laughing HHH) ... I remember the lab technicians being frustrated and overburdened because of the number of units brought in each day by the previous team, which they had to process every day. Of course, their skills, communication and connections with PHMD were better due to their extensive expertise; we are talking about nurses with 15 to 20 years of experience.*

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Their experiences in the oncology and paediatric nursing field had shaped their practice. The midwives' negative perception of the current UCB team may have stemmed from their experience with the previous UCB team, comparing the current team with the old UCB team. Although both previous and current UCB teams worked under the same leadership and policies, their capabilities in areas such as communication and initiative differed greatly. The main differences between the two teams could be ascribed to the differences in their experience in the field. In other words, the current UCB team did not have the required soft skills due to the lack of concrete experiences with oncology patients and nursing departments, this resulted in the declining UCBC rates.

#### 5.2.3.3. Structure Three: Emotional demands

Within the data it was observed that UCB nurses appeared to be emotionally exhausted, partly as a result of their inexperience. In relation to the causal structure, this structure depicts one of the consequences of their inexperience. This structure indicates that the job of a UCB nurse comes with a great deal of stress, both current and previous UCB teams experienced this, as shown in the quotes below. However, due to their inexperience, the current UCB team appeared to have found it difficult to manage this level of stress.

This was best explained by UCB nurse 4:

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**UCB nurse 4:** *It is really challenging to establish relationships with PHMD staff or acquire access to them, especially at the beginning because they have their own culture and approaches to doing things. It is uncomfortable to ask someone for help with something that's not part of their job description. And because of how easily they can misinterpret our actions, you must learn to always act with caution and sensitivity, and*

*how to be positive, smiling when interacting with them... We rely on them to help us complete our task, but it is exhausting to have to constantly explain yourself to earn their trust so they will let you know when they find a good quality cord that may provide a good UCB unit... This work is never simple to do. It is difficult since you must satisfy everyone. However, it is not impossible, and this comes with time; you must learn to be patient; it is like putting on a mask.*

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UCB nurse 4 noted that the stress she was experiencing came from having to navigate interpersonal relationships in the professional space. Working in a different hospital, UCB nurse 4 suggested that there was some reticence when asking for support from other staff members. Maintaining and developing trust with the other PHMD staff was difficult. In the above quote she alluded to “putting on a mask” where she implied the need for a carefully curated façade when working with the PHMD staff and that her emotional exhaustion was partly due to having to maintain that façade at work.

UCB nurse 1 further explained that this emotional exhaustion may also come from working with mothers.

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**UCB nurse 1:** *Although the recruitment process seemed straightforward, it required time and effort and skills to gain the mothers’ trust. As during the labor, the mother needs you to be patient and compassionate so that you may help her feel more at ease. You may start talking to her about UCBD when the time is appropriate, and the contractions are less intense. But you cannot expect her to donate if you just go into the delivery room without introducing yourself and establishing any kind of rapport with her. This is where the new team falls short; they lack the necessary experience to identify the best time for recruiting the mothers. They can progress more quickly with training and constant monitoring.*

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Apart from having to gain the trust of other PHMD staff, UCB nurses also needed to gain the trust of the mothers that they recruited. In addition to time, effort, and skills, UCB nurses also needed to be patient and compassionate in order to gain trust and establish rapport. UCB nurse 1 also noted that the current UCB team lacked skills in this area and that more training was required for them to develop these skills.



In the two quotations above, a similar idea emerged: the need for more time to develop skills in managing this emotional labour upon the UCB nurses. UCB nurse 5 synthesised these very clearly below:

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**UCB nurse 5:** *...and they [the UCB management] should be patient as well and stop judging us because we can do better with time... To be honest, there were times when I wanted to give up because everyone blamed us for the low collection rate, and I may do so at some point because the amount of stress and demand in this job is unbelievable.*

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UCB nurse 5 emphasised that the UCB nurses needed more time to learn the soft skills that would help them deal with the emotional labour. She also indicated that the nurses were under an immense amount of stress.

UCB nurse 2 explained that stress was the reason she decided to leave her post as a UCB nurse, despite her experience she felt immense pressure.

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**UCB nurse 2:** *I felt sorry for myself. Why should I suffer all this stress? I decided to move back to the nursing field; less stress, better professional development, new work environment, better job security and no more threat of losing my job. I thoughtfully weighed the advantages and disadvantages of being a UCB team member and I made the decision to leave.*

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In this structure, the current UCB nurses voiced the need for more time and training to be able to handle the stress and emotional toll of UCB collection. As UCB nurse 1 had put it, this was due to the current UCB nurses' inexperience and lack of training in this area. UCB nurse 2 showed how these stressors mounted during her time as a UCB nurse and eventually forced her to leave her position. This demonstrates the situation's demands, which can be too much even for an experienced UCB nurse.

To conclude this mechanism, the inexperience of the UCB team had many consequences, this was not curtailed by management due to the lack of appropriate training given. Their lack of experience, and therefore expertise, meant that their day-to-day activities were inevitably more difficult and stressful, as outlined by the structures described above. It cannot be overstated that the failures of the programme do not lie with the individuals in

the current UCB team, only that their lack of expertise resulted in them being unable to fulfil their duties. The UCB team was thus unable to develop a supportive and collaborative relationship with PHMD and parents and could not build trust with either participant group, therefore collection of UCB was suboptimal.

On the other hand, the previous UCB team was able to leverage their cultural similarities and stronger communication skills, they took more initiative in ensuring the success of the UCB programme. This was largely due to them having more experience as nurses prior to being part of the UCB team. While they were similarly under the same ambiguous leadership structure and policies, they had worked with these circumstances more successfully than the current UCB team.

The contextual condition of the mechanism, again, was the Saudisation scheme. Despite their lack of expertise, the UCB nurses were employed partly due to their Saudi Arabian native status. Although they were qualified nurses, they had just graduated and were not familiar with several aspects of the process of UCB from collection to transplantation. They could not therefore effectively communicate the benefits and the value of the programme. The Saudisation scheme is deemed as the contextual condition in this mechanism as the drive to increase reliance on local manpower has allowed the structures above to perpetuate.

### 5.3. Conclusion

In this chapter, three causal structures were explicated. Firstly, the ambiguous leadership and lack of supportive supervision. This causal structure affected all participant groups as all groups were misinformed about the programme in some way, due to the setup of the programme. The second causal structure was training and education, this highlighted the lack of effective UCB education for mothers and the lack of appropriate training for UCB nurses. The last causal structure on the inexperience of UCB nurses explained the various interpersonal issues that emerged from the UCB nurses' lack of experience and soft skills.

The three causal structures that have been outlined in this chapter proposed three possible generative elements of the UCBC programme. Abduction and retroduction served the purpose of highlighting and diagnosing the main issues of the programme, which ultimately resulted in the decline of collected UCB units. All data were gathered on site either through interview responses, from my own observations or from documentation. The triangulation of data confirmed the veracity and validity of the three causal structures. Although the causal

structures had generative power, they interacted closely with each other and the other structures and the contextual conditions. In writing this chapter they were isolated and highlighted to show their importance with greater clarity.

This analysis identifies the key areas of the programme that were failing. CR analysis stresses that explicating the isolated structures reduces excessive and unnecessary information to highlight the importance and causality of singular structures. However, once these have been extracted, there is a necessity to discuss the wider picture and bring those causal structures to the empirical to explain and understand the situation in its entirety.

The following discussion chapter de-contextualises the three causal structures and their interactions that ultimately led to the declining UCBC rate. The discussion also explores the wider context again and brings the phenomena back to the empirical, from the perspective of the three causal structures and their influence on the whole situation. The discussion chapter also contains recommendations, many of which are largely based on the issues associated with the abducted causal structures.

# Chapter 6. Discussion Chapter

## 6.1. Introduction

This study aimed to uncover the causes of the declining UCBD and UCBC rate in a public UCBB in KSA. CR analysis was used to fulfil the research aim by exploring the barriers and facilitators affecting UCBC. From the descriptions provided by participants and other data sources, the structures or factors affecting the programme were made known. Following on from Chapter five, the discussion includes an exploration of the open system, namely the UCB programme, in KSA. It explores the complex interaction between causal structures, mechanisms, structures, and empirical events which led to the decline in the UCB units collected.

In this chapter the three causal structures underpinning these barriers are recapitulated prior to a discussion of the key barriers of the programme. These barriers are then discussed from a CR ontological perspective with a focus on how they contributed collectively to the systemic failure of the UCB programme. Facilitators of the UCB programme will then be discussed, drawing from research and wider literature. The chapter will then expand on the recommendations touched upon in the discussion of the barriers and facilitators and conclude with a consideration of the strengths and limitations of the study.

## 6.2. The Barriers

In the previous chapter, three key causal structures were elicited from the abduction and retroduction process in the analysis:

1. Lack of supportive supervision and leadership
  - a. The lack of clear leadership in the programme and appropriate supervision resulted in confusion around the disparate policies, logistical issues, and the lack of incentive to take part in the programme. More saliently, this resulted in a power vacuum, which then led to the social exclusion of UCB nurses and sanctioning of midwives.
2. Inexperience of UCB nurses
  - a. Current UCB nurses lacked the required soft skills and wider nursing experience to develop a good working relationship with the PHMD midwives and handle the requirements of the parents.
3. UCB programme education and training

- a. Parents' lack of understanding about the programme and educational background allowed superstitions and other cultural practices to dissuade them from donating. This is exacerbated by the poor timing of consent-seeking procedures.
- b. UCB nurses were poorly trained in the UCB programme.

These causal structures led to three key barriers being identified: lack of supportive supervision and leadership of the UCB programme, inexperience of UCB nurses and the lack of education for parents, UCB nurses and midwives on the UCB programme.

These barriers interact closely with each other within a complex system, which then collaboratively contributes to a systemic failure within the programme. These barriers are first discussed individually with reference to the wider literature and then synthesised within the CR ontology.

### 6.2.1. Poor leadership and supervision of the UCB programme

There was an absence of clear instructions to manage the disparate policies, strong leadership and oversight of the programme, and management of the conflict between the two settings. The lack of training and support for the UCB nurses, incentives for midwives to participate, and appropriate education for parents were also reasons behind the lacklustre efforts in the UCBD and UCBC. Therefore, the poor leadership and supervision of UCB programme is a key barrier since many of these are responsibilities of the leaders of the UCB programme.

#### 6.2.1.1. Poorly developed infrastructure

The issues within the higher-level management of the programme suggest that there were issues in the infrastructure of the programme. Multiple issues have been identified within the research:

- interpersonal conflict and lack of communication between the staff from the two settings
- lack of management of the UCB nurses
- lack of adequate training, incentives, and education for the UCB staff and parents.

These lead to a question of whether the current UCBB infrastructure is fit for purpose. In the context of this research, infrastructure refers to a network of institutions that support the use of UCB from governmental positions to the local family doctor during prenatal appointments. This infrastructure involves individuals and larger organisations that impact

and are impacted by the UCB programme, including mothers, UCB team, managers, laboratory staff, partner hospitals, obstetricians, the Ministry of Health.

Williams (2018) argued that a strong supporting infrastructure needed to be established in the UCBB field, to ease the process of collection and use of UCB. The literature mainly focused on training and reviewing the knowledge of healthcare professionals and parents. Published research regarding managerial and organisational decisions in UCB banks is limited, however, Williams' article argued that ignoring the UCB bank infrastructural problems would result in its downfall.

“A properly developed infrastructure for the collection and storage of UCB will do much to alleviate the severe shortage of lifesaving stem cells needed for transplantation and to facilitate research...” (Hansard 2010, p.1).

Hansard (2010) echoed the same sentiment with regard to the importance of developing networks and communication within the UCB to facilitate the various functions of the programme. These include collection, donation, storage, searching for matches, research, and application of the UCB.

In other words, if UCBB infrastructures are not properly developed and maintained, the UCB programme is likely to fail. In this research, poor leadership and supervision of the programme were identified as key barriers, which have close interaction with other issues. Instances of these issues include the communication between the two settings, management of interpersonal conflict, incentivising and motivating participation in the programme, as well as providing adequate education and information for parents to make informed decisions.

Poor leadership and the lack of supervision may potentially serve as a barrier to resolving the other barriers and issues of the programme. Further research is required to explore the wider infrastructural issues within the UCBB and the other functions it serves, as this research only focused on the UCB programme, UCBD and UCBC at one hospital specifically. There were potentially other issues within the infrastructure of the UCBB relating to how the programme was being run with other hospital partners, how the UCB units were being processed, stored, and used and how it worked within the healthcare system in KSA. As Williams (2018, p.481) concluded, “The continued existence of UCBB infrastructure depends on its continued attractiveness to current and future clinical users, as well as bank managers' willingness to reflect on its current state.” The onus is on the leadership and managers of the UCBB in KSA

to review and reconsider the current infrastructure to ensure that it is still attractive to those who collect, those who donate and those who use the UCB units.

Infrastructures external to the UCBBH UCB programme also present obstacles to the success of UCB collection. In KSA, there are two public UCB programmes, one run by the UCBBH and another by the National Guard Hospital. However, there is a lack of unification of the UCBB systems in KSA despite both being national programmes. As a recommendation for further consideration, there is a need to explore ways of unifying and streamlining these public UCB programmes to minimise the duplication of effort and cost, much like the single unified national UCB programmes in Italy and the UK.

The Italian studies explored in the literature review (Chapter two) showed how a strong and well-developed UCB infrastructure led to better awareness and understanding of the programme (Parco et al. 2013). Parco et al. (2013) found that many of the parents they interviewed were aware of UCBD for public banking. This was due to both hospital and governmental policies advocating for UCB education for all mothers. Parents were also informed about the option for UCBD early in the pregnancy in Italy, contributing to the general success of their programme (Grieco et al. 2018). The narrative of the UCB policy was echoed throughout national health organisations. This positive link between regulated, solid infrastructure and higher awareness of public UCBD was also echoed in (Grano et al. 2020). They found that over 97% of mothers had some level of knowledge of UCBD. Wider and more complex infrastructures, such as that in Italy's UCBC, appeared to be lacking in KSA as demonstrated by this study and UCB managers in KSA need to give it more consideration.

#### 6.2.1.2. Lack of clear policies and standardised procedures

As a part of the infrastructure, this study also found a lack of clarity in the policy and standard operating procedures for UCBC and infection control, this was further confused with the existence of different policies and practices of the UCB programme and PHMD. The lack of clarity in the policy is not unique to this UCB programme. The UCB programme in Jordan, Abdulrazeq et al. (2020) noted the absence of policy in their study. The majority of obstetricians in their studies claimed that the absence of guidelines in hospital policy, regarding UCBC, had been a deciding factor for not collecting UCB. Over 75% of their sample had stated that their hospital did not have clear policies on UCBC or screening for infectious diseases. Similarly, in this study, the lack of clarity on policy dissuaded PHMD midwives from collecting UCB units, this led to reduced opportunities for collecting the units. It also led to units being wasted due to a misunderstanding of the viability period.

Apart from the procedural issues, the varying practices and approaches towards infection control were another source of interpersonal conflict within the collaboration between midwives and UCB nurses. For example, the number of chlorohexidine sticks used for cleaning the collection site. Clearer guidelines and policies need to be developed and enforced by the leaders and managers of the UCB programme, also the staff and partners responsible for the collection of UCB units should be properly informed about these. However, there is generally little research into UCB regulation on hospital policy and management.

The unclear policy wording on the timing of consent is also a barrier to UCBD. The current policy states that consent needs to be obtained prior to the onset of labour but does not specify exactly how far prior to labour UCB nurses should obtain consent. There is also the issue of UCB nurses not adhering to policy by seeking consent for UCBD from mothers only during labour. In Abdel Fadeel et al.'s (2018) survey of 78 antenatal nurses in Egypt, 38% of the participants remarked on the poor timing of obtaining informed consent (at the time of labour) as a barrier to UCBC. In fact, the top barrier (78% of participants) emerging from their study was generally the policy issues and procedures at the hospital.

In addition to the lack of clarity in the policies on UCBC procedures, policies and supporting infrastructures to facilitate the development of UCB nurses and midwives were generally lacking. This is indicative of an absence of supportive supervision of the UCB programme.

#### 6.2.1.3. Lack of supportive supervision and developmental opportunities

In order for employees to be given the assistance, direction, and resources they require so that they can carry out their responsibilities successfully, a supervisor's function in the organisation is essential. In addition to poor leadership, the lack of supportive supervision is one of the main problems that can have a detrimental effect on staff and organisational outcomes, according to Marquez and Kean (2002). High employee turnover is one issue, which stems from a lack of supportive supervision. Staff turnover rates are higher and institutional knowledge is lost when employees feel under-appreciated and poorly supported in their jobs (Marquez and Kean, 2002). The high turnover stipulated here can be attributed to employee contentment.

To summarise the relevant findings presented earlier, the previous UCB team in this study left due to professional issues in the department, particularly concerning their career progression. The current UCB team was also similarly deprived of career development opportunities resulting in unhappiness about their prospects within the UCB programme.



UCB nurses mentioned that they were promised promotions and training at Barcelona to advance their careers, this did not materialise. The fact that they belonged to the laboratory and nursing departments neither of which took responsibility for the UCB nurses' development further exacerbated the problem.

In their interventional study, Sward et al. (2019) found that the group of obstetricians who had received hands-on training with an experienced UCB collector was more likely to collect UCB in the future. The obstetricians received feedback, written and verbal, and this supportive supervision led to lower UCBC costs and statistically higher correlation with parent satisfaction with the service. This highlights the importance of training for the UCB collectors and its impact on the success of the UCBC.

The lack of supervision and developmental opportunities also impacted on the midwives. For the PHMD midwives, the UCB programme and its connected tertiary hospital promised hope of career progression. They had expectations of training at the more prestigious sites through the programme and benefitting professionally in ways their midwifery position could not afford them. Better leadership and infrastructure that supported the growth of the midwives, and UCB nurses, would have turned this into a facilitator or incentive to encourage more proactive participation. This is a possibility, the previous UCB team provided training and developmental opportunities for the midwives, which led to a better appreciation of the UCB programme by the midwives.

In some ways, developmental opportunities offered through the UCB programme partnership are particularly crucial to the PHMD midwives. PHMD midwives were earning less than the UCB department yet had a considerable workload. For this group, earning potential was linked to their educational background. PHMD midwives were educated to a diploma level whereas the UCB department were educated to degree level. With the varying levels of experience in education, income, and outside societal structures, came various concerns regarding long-term goal attainment. It should be noted that women made up 100% of KSA's midwives including the participant group of this study (Altaweli et al. 2020). The PHMD participants were nearly all mothers, wives or carers and had to take on tasks attached to their multiple roles (Hvidt 2018). The PHMD midwives had concerns about raising their children, being available for their partners and taking up home duties as well. In Chapter five (causal structure one, section 5.2.1.6), concerns regarding the PHMD midwives' access to accredited training hours were explored as an incentive to encourage voluntary UCBC. During abduction, it was clarified that for the PHMD staff, training with a reputable, tertiary hospital

held hope for them. There was a certain privilege in being associated with a well-known hospital such as UCBBH, the midwives felt they could benefit professionally through this partnership, supporting their own career advancement. PHMD midwives assumed they would benefit from the partnership programme on a professional level through schemes such as CME hours and other training opportunities.

In conclusion, poor leadership and lack of supportive supervision were key barriers in the UCB programme. However, this can be seen as a circular problem, poor leadership results in infrastructural weaknesses but these weaknesses cannot be resolved until leadership improves since the leadership is also part of the UCBB infrastructure. Poor leadership also created other barriers which affected the UCBC rates such as the UCB nurses' inexperience and the education of parents.

## 6.2.2. Barrier 2: UCB nurses' inexperience

The UCB team was made up of inexperienced members who could not be proactive in order to make up for the lack of supportive supervision and leadership. Due to lack of experience and training, the current UCB team was unable to effectively recruit mothers nor maintain positive professional relationships with their PHMD colleagues. This study revealed that the previous team had exhibited effective habits and practices to the UCB department due to their expertise. In essence, the previous team showed soft skills that were not part of the UCB team training, they were the result of experience gained from working in the field of oncology and stem cell transplant. They had also worked with cancer patients who relied on available UCB units, thus developing their values and beliefs.

The inexperience of the UCB nurses is a significant barrier to UCBC. It meant that the hired UCB nurses were lacking in transferrable skills and practices that could have benefitted UCBC. These soft skills are required when working with hospital partners and donor parents and to manage the emotional labour that comes with the job. At the end of the discussion, the national agenda, Saudisation, which influences the hiring practices of nurses is raised as a factor that affects this barrier.

### 6.2.2.1. Lack of transferrable skills, practices and habits

With experience comes expertise and therefore the tacit knowledge required of a UCB nurse, this can be difficult to break apart for analysis. This research does not have the scope to explore the specific content of the tacit knowledge that is expected of a UCB nurse in the context of UCBC. However, the data presented and the retroduction analysis demonstrated

that the UCB nurses were indeed lacking in some tacit knowledge. In this context, tacit knowledge refers to skills in effective communication with colleagues, other organisations, patients, and problem-solving skills. This was evident in the way they interacted with the mothers and midwives. For example, during my observation, after UCB nurse 4 had spoken to a mother, the mother asked a midwife to explain what UCB meant. This suggested that the required tacit knowledge in communicating and educating patients was somewhat lacking in the current UCB team. This can be seen as a product of lacking experience generally as a nurse.

When an individual moves within a field of expertise, they are able to pick up practices and habits that may make them more effective in performing their task (Scott 2014). For example, the previous UCB nurses had been adept at educating mothers on the need for UCBD, they worked well with midwives because of their previous experiences as oncology nurses. The value of UCB units was highly appreciated by this team because they have experienced, with patients, what happens when UCB units are not available. However, merely having prior experience is insufficient, according to Scott (2014) individuals carry over habits and practices that are valuable to them. The previous UCB team educated mothers during antenatal appointments, outside of their mandated tasks, because of how valuable UCB units were to them. The current UCB nurses, on the other hand, lacked the same finesse in communication and lacked the general tacit knowledge required to work effectively as UCB nurses in the department. Being newly qualified the current UCB nurses had little prior experience to draw on and which could have been of benefit in their current position. Also, they had not been appropriately trained or taught on the job to appreciate the value of UCB units.

#### 6.2.2.2. Lack of soft skills

The act of caring is founded on morality and humanity and involves taking care of another person. Caregiving is influenced by a nurse's soft skills (Hussein and Elsaïad, 2021). Soft skills are defined as the ability of individuals to relate to others successfully, perform well, and accomplish their goals (Asbari et al. 2020). According to Foster et al. (2015), someone with good aptitude for soft skills will demonstrate the capacity to manage one's own emotions, flexibility to deal with changes and adapt, optimism, ingenuity, and initiative. In this study, the absence of soft skills was a clear barrier to obtaining trust from parents and impeded on increasing the rate of UCBC.

Researchers Ernawati and Bratajaya (2021) found nine types of soft skills that a nurse would benefit from in order to be effective in their role. They categorised these soft skills into three

broad categories: personal skills, social skills, and self-regulation of the learning process. Personal skills included the activities that required the caring and nurturing aspects of nurses. Personal skills also included the notion of self-motivation and control as nurses, they found, required the skill of withstanding and de-escalating conflicts that can arise in high-pressure environments. Additionally, they argued that self-motivation was required as a personal skill to remind oneself of the virtues of the position and the importance of their role in their society.

The current UCB team lacked some of these skills due to their inexperience in the field. It was seen in their responses in interviews, and in further analysis, that the UCB team were ill-equipped at handling opposition. Albeit the UCB nurses required some shielding from hostile workplaces, they did not have the tools to handle conflict that arose as a result of the lack of communication from UCB leadership. The previous UCB nurse, on the other hand, were better able to manage their relationship with the midwives because their stronger set of soft skills and experience in the nursing field.

Strong social skills are an important part of being a nurse because they are required to work and interact with people of all backgrounds. Thus, nurses need to have outstanding social skills as argued by Ernawati and Bratajaya (2021). According to them, nurses are required to be skilled in hospitality, flexibility and adaptability. In this study, there were a number of parents with differing levels of superstition and disbelief in the UCBB cause. Some parents were aware of the health benefits for UCB recipients, while others had never heard of UCBC and were sceptical about the reasons for collecting UCB. The sceptical parents had cited their belief about black magic or the parameters of their Islamic faith regarding bodily fluids and the concept of mixing lineages.

Ernawati and Bratajaya (2021) argue that nurses need to be adaptable as they will come across a broad spectrum of people with different backgrounds and beliefs. Thus, nurses should be able to relay key information to patients in an objective manner. In this study, the new UCB nurses lacked the ability to be adaptive to their patients as they had no experience and no training in approaching mothers and families with regard to collection. Developing their communication style and approach to parents would help them to effectively communicate the nature of the UCB programme and thus increase the UCBC rate. Alahmad et al. (2020) also cited that religious and cultural beliefs were ethical barriers to UCBC as mothers would simply refuse to donate UCB if they were unclear about the religious

parameters regarding UCBD. This was seen multiple times in this study, mothers did not want to jeopardise their good deeds by partaking in a practice that may not be permissible in Islam.

More importantly, the lack of experience and soft skills were not mitigated by supportive involvement, such as dedicated training in the recruitment of mothers, best practice or observing the team in their practice for support. Rather, the UCB team's inaction led the leaders of the department to reutilise them in different departments – further exacerbating the effects of the causal mechanisms. For example, in Hussein et al. (2021), a quasi-experimental study with a pre-test and post-test design was conducted in Egypt to explore the impact of a soft skills training programme for nurses. Participants underwent an education programme with one session on knowledge and the importance of soft skills for nurses and another session on soft skill training on communication with other staff members and patients. The study found statistically significant differences between the nurse participant's knowledge, job performance and soft skills pre and post intervention. This suggests that training courses have an important role to play in developing the UCB nurses' soft skills and its absence adds to the difficulties caused by inexperience.

Raeissi et al. (2021) suggested that responsibility for developing nurses' emotional intelligence and self-awareness, skills that would be important for UCB nurses when recruiting donors, falls on the hospital managers. Other researchers such as Kim and Yi (2015) have argued that these skills need to be taught in higher education institutions, while Ernawati and Bratajaya (2021) similarly asserted that these skills need to be part of the curriculum itself and embedded within the learning process with ample and consistent guidance. Regardless of it being a training programme for graduate nurses, or part of the higher education curriculum, supervisors and educators have a responsibility to develop nurses' soft skills.

The researchers Ernawati and Bratajaya (2021) delineated their soft skills categories to develop a training programme for inexperienced nurses in Indonesia. They argued that nurses with underdeveloped soft skills face hardship in their daily activities and increased conflict. Ernawati and Bratajaya (2021) also state that these barriers to the job role further increase nurses' dissatisfaction with their role and burden them with unnecessary emotional labour and workload. In the next section, emotional labour in the research field and what was seen in this study will be explored and discussed.

### 6.2.2.3. Lack of emotional labour management strategies

Haw et al. (2020) highlighted the emotional labour that was associated with UCBC for HCPs as a factor that was not understood by management. Emotional labour refers to the effort, planning, and control required to express and manage emotions in order to meet the expectations of a particular job or role (Kusakli and Husmenoglu, 2021). As a result of various factors, including spending more time with patients and having greater empathy and emotional sensitivity due to the majority of occupational members being women, nurses undergo a great deal of emotional labour. Burnout affected performance and job satisfaction for employees and increased the rate of staff turnover for the company, these are all consequences of emotional labour (Kusakli and Husmenoglu, 2021). This was seen in this study, the previous UCB team had left their roles partly due to the additional emotional labour and burnout it had caused, with little possibility of being able to progress professionally as compensation.

Researchers have identified two forms of emotional labour, surface acting and deep emotional labour (Biron and Van Veldhoven 2012). Surface acting is a type of emotional labour that involves suppressing one's true feelings and expressing emotions that are not genuinely felt in order to comply with the job requirements. For example, the manner in which mothers were approached suggested how the performance of the current UCB team was perfunctory. Field notes observations noted that UCB nurses would approach mothers at an inappropriate time during labour, using rather contrived tones and expressions in their interaction with the mothers when asking for donation. This demonstrates a lack of empathy for the mother during labour and the inability to understand the inappropriateness of their actions.

Deep acting emotional labour, on the other hand, involves managing one's own emotions to genuinely feel and express the appropriate emotions for a given situation (Biron and Van Veldhoven 2012). This requires a greater level of emotional regulation and empathy. Nurses may need to manage their own emotional reactions and express empathy towards a patient who is experiencing intense symptoms - such as labour in the case of the UCB nurses in this study. Biron and Van Veldhoven (2012) argued that these intense environments need service workers to provide additional services to alleviate the intensity of the environment. Converse to the example given in the previous paragraph, the previous UCB team were emotionally cognisant of the mothers' plight. They had a deeper understanding of the difficulties in deciding whether to donate. Due to this connection with expecting mothers, the previous

UCB team ensured that mothers felt secure in their understanding of UCB before active labour and before asking for UCBD.

Haw's et al. study in 2020, highlighted the emotional labour required for participating UCB collectors to navigate the maternity ward amongst multi-disciplinary staff. The study found that UCB collectors must vigilantly monitor and display sensitivity to other HCP's needs. This included managing their own emotions and using interpersonal skills to support the emotional state of other nurses. Nurses needed space and time to manage their stress, gaining acceptance by other HCPs required careful negotiation of when and how to be present and available. In this study, the previous UCB team had shown that they were capable of navigating these complexities. When interacting with the PHMD midwives, they displayed sensitivity and an understanding of the differences between the staff at the PHMD and themselves, they also showed gratitude when PHMD staff helped with collection of UCB.

Hur, Moon, and Han's (2014) study looked into the effect of age on the ability to manage and exhibit the two types of emotional labour. The study found that older nurses and nurses with more work experience have deep acting capabilities, which helped them to manage emotional labour. The connection found by Hur, Moon and Han (2014) was similarly observed in this study. The previous UCB nurses who were older and more experienced were more effective in collecting UCB units. This was because they had a vested interest in the programme and an understanding of the value of the units, this stemmed from their background in oncology, alluding to their deep acting capabilities. The current UCB team, who were on average younger than the previous team and had less work experience, were less able to demonstrate this level of skill in deep acting management of emotional labour.

Furthermore, in Biron and Van Veldhoven's (2012) study, it was concluded that surface acting emotional labour may contribute to greater mental exhaustion. However, deep acting emotional labour had no meaningful impact on the level of exhaustion. In this study, the previous UCB team had more interest in collecting UCB as they had seen the importance of the units in their fieldwork as oncology nurses. Such deep acting emotional labour had less impact on their emotional exhaustion, which would also explain why the previous UCB team were in their roles for 5-7 years. The current UCB team who had less experience and demonstrated more indication of surface acting emotional labour, on the other hand, had showed signs of burnout after only three years. Kusakli and Husmenoglu (2021) similarly argued that nurses with more work experience were expected to be more proficient at evaluating and managing emotions, proficiency in these areas is likely to lead to better job

satisfaction. Conversely, Theodosius et al. (2021) conducted a cross-sectional study to see the effect of surface acting on nurses in the UK. The study found that surface acting in jobs that involved dealing with patients and coworkers could increase the likelihood of burnout and wanting to leave the role.

In conclusion, deep acting emotional labour appears to be a more effective way of managing the emotional burden on the UCB nurses than surface acting emotional labour (Biron and Van Veldhoven 2012; Hur et al. 2014; Haw et al. 2020; Kusakli and Husmenoglu 2021; Theodosius et al. 2021). In this study, the previous UCB team demonstrated more proficiency in deep acting emotional labour, which may explain how they appeared to burn out more slowly than the current UCB team (who appear to rely on surface acting to manage their emotional labour). However, deep acting emotional labour ability is tied to the age and work experience of the nurses, calling into question the hiring practices and work experience requirements of the job as a UCB nurse. This subsequently raises another complex factor related to Saudisation as a political and national agenda.

#### 6.2.2.4. Saudisation as a factor

While Saudisation policies, along with the Vision 2030 national goals, prompted a rise in the recruitment of Saudi workers, it can also lead to the detrimental consequence of employing less experienced (newly graduated) nurses in roles that require more experienced practitioners. Alboliteeh et al. (2017) surveyed 1198 Saudi Arabian nurses and found that Saudi Arabian national nurses were relatively young with a mean age of 27 and inexperienced, with 77% having less than five years' experience in nursing, in comparison with other countries like Singapore and Australia. Alboliteeh et al. (2017) attributed this to Saudisation and reported that it was heavily impacting on the nursing labour force. Hence the issue of Saudisation is not isolated to the UCB team, it can be seen as having a broad industry-wide impact on the general youth and inexperience of the healthcare workforce. While the Saudization programme is essential for ensuring an adequate domestic workforce in the country, it is crucial to execute it with caution to prevent any potential consequences that may compromise the quality of healthcare services.

UCB nurses in this study were new graduates when hired into the UCB team as a result of Saudisation. Baker (2020, p. 214) found that the challenges they experienced included "role expectations, lack of confidence, workload, fear, and orientation issues, while other factors such as physical environment, responsibility, support, and professional development created a sense of dissatisfaction among nursing professionals." Saudisation also brought with it the



need for orientation, supervision and support to combat the general lack of experience of nurses (Baker 2020), which was evidently lacking in the UCB team.

Saudisation is a long-standing national policy that started in 1975 (Abouraia 2014), and vision 2030, which started in 2016, seeks to similarly improve the employment of Saudi Arabian nationals (Alomi et al. 2018). Nationally, there is gathering momentum for labour policies that encourage preferential employment of Saudi nationals. This is not considered a barrier as these were the circumstances in which the UCB programme was conceived, however, the inexperienced UCB nurses hired as a result of these policies have resulted in a barrier that needs to be managed. In Mebrouk's (2018) constructivist grounded theory research on Saudisation in nursing. One of the key factors that has contributed to the ineffectiveness of Saudisation is the lack of support provided to nurses, which is characterised by mounting conflict between Saudi student nurses and expatriate nurses in the clinical settings. This phenomenon is similar to the interpersonal conflict between UCB nurses and midwives as observed in this research. To support this influx of less experienced Saudi national nurses in the industry, Mebrouk (2018) suggested a need for healthcare organisations to implement and facilitate mentorship and preceptorship programmes for both Saudis and expatriates to prepare them with the skills and knowledge required when working together in the clinical setting. Mebrouk (2018) also encouraged senior nurses to step in and support junior nurses and to help resolve conflict where it arose. Mebrouk's (2018) research appears to mirror some of the findings in this research, however, while these recommendations and those by Baker (2020), may appear to be helpful for UCB nurses, it is important to also be aware that the complex infrastructural and leadership issues make it difficult for these to be implemented successfully.

### 6.2.3. Barrier 3: Lack of training and education for parents, UCB nurses and midwives on UCB programme

Aside from the UCB team, the donor parents and midwives also do not receive sufficient training or education on the UCB programme. The parents were not educated about UCB at an appropriate time to enable them to give informed consent. UCB nurses and midwives require a more thorough understanding of the programme to be able to fulfill their responsibilities appropriately.

### 6.2.3.1. Lack of education for parents on UCB programme

In the literature, the need for training and education on UCBB procedures and associated treatment was well explored. Padmavathi (2013) discovered that parents were initially unaware of UCBD and that education sessions resulted in around 70% of their sample demonstrating satisfactory UCB knowledge. Similarly, many of the mothers in this study wanted to learn more about UCB, they felt that with more knowledge, they would have consented to UCBD. In Zomer et al.'s (2021) study, pregnant woman's awareness and knowledge of UCBB was assessed using a survey to identify the causes of poor donation rates in Brazil. They found that 35% of the surveyed women declined due to their lack of knowledge of UCBB.

Notably, the demi-regularities revealed a distinction between mothers with higher education and their affinity for UCBD compared with those with only high school education. This connection could not be explored due to the small sample size (nine mothers were interviewed) and the qualitative nature of this study. However, the link between parents' education level and their knowledge and attitudes towards UCB have been reported by several authors. Matsumoto et al.'s (2016) survey conducted at six hospital sites in Jordan with 899 participants found that parents who were university-educated were more likely to donate CB. In Lebanon, Saleh (2019) found that parents with graduate level education were more aware of UCBB, more likely to seek UCB education and had a more positive attitude towards public CBB. In Iran, Azadpour et al. (2018) reported that in their participant group, mothers who had completed further education were more likely to donate UCB than those who had not.

The time point at which parents were given information about UCBD also had a significant impact on their inclination to donate. Grieco et al. (2018) recommended giving gentle reminders in the mother's third trimester to increase the likelihood of increased donation rates. Those that were only told once, at a late stage of pregnancy, were less likely to donate UCB. In this study, mothers were only told of the possibility of donating UCB when they were in active labour, and thus were less likely to donate.

Here the UCB nurses' lack of experience and the lack of training and knowledge interact closely with the parents' overriding superstitions and religious beliefs preventing them from consenting to UCBD. Misconceptions about UCBD and about religious permission for donation and superstition heavily influenced mothers' decisions since UCB nurses were unable to clarify and appropriately educate them. These sociocultural and religious reasons

were also observed in the literature about general blood donation. Abdel Gader et al. (2011) reported that KSA had various cultural and socioeconomic elements that restricted blood donation. According to the authors, participants' families or communities may discourage them from donating blood because they are worried about potential health hazards or the mixing of various people's blood. The authors had concluded that these fears were based on a lack of clear awareness of the Islamic ruling on blood donation. Their main finding was that overall attitudes to donating blood (when aware of potential benefits) was positive. When appropriately educated about sociocultural and religious barriers, mothers had demonstrated that they were more inclined to donate. However, UCB nurses were ill-equipped to effectively educate mothers due to their lack of expertise in the UCBC field.

Education appears to be the cornerstone of the cultural and religious issues that mothers face and which prevent UCBD. The findings of this study revealed a certain paranoia by mothers who were concerned that workers at the hospital would use the UCB to perform black magic on them. Such paranoia can be allayed with assurances of confidentiality in the donation process. In Asamoah-Akuoko et al.'s (2017) scoping review on blood donor's perceptions in Sub-Saharan Africa, African blood donors were concerned that donated blood would be used for occultism and rituals. This was attributed to the lack of knowledge about blood donation, which then spurred fears surrounding how donated blood was being used. These fears about black magic and UCBD similarly stem from a lack of understanding about how UCB units are stored and used and how confidentiality is maintained. Educating donors would help to prevent lack of knowledge from creating unfounded fears, which then act as a barrier to donation.

Mothers also have concerns around blood brotherhood where the recipient of the UCB unit is bonded with the UCB donor baby by blood. This concern is an extension of the Islamic belief that children who are breastfed together are considered breastfeeding brothers and sisters, and thus siblings by connection (Subudhi and Sriraman 2021). Mothers were concerned about potential issues around incestuous marriages in the future. However, there was a religious ruling in 2003 in KSA that permitted the donation of UCB units (Matsumoto et al. 2015) and unlike breastfeeding siblings, there is nothing in the Islamic law (Sharia) that discusses blood brothers. Similar to black magic, mothers need to be educated appropriately and informed of the Islamic ruling to dispel these concerns. As a patriarchal society, fathers need to be part of the UCBD decision making process, to receive education on the programme and to be provided with the Islamic ruling alongside mothers.

Although cultural, religious and spiritual beliefs can be considered as barriers to UCBD, lack of knowledge appears to have enabled these barriers to emerge through fear and misinformation. Therefore, parents' knowledge of the UCB programme is the key barrier here.

#### 6.2.3.2. Lack of training and education for UCB nurses and midwives on UCB programme

In this study, there were instances of PHMD midwives not knowing key information regarding UCBB. There were a few implications from the lack of knowledge regarding collection that were explored. Namely, the immediate consequence was that not knowing about criteria or UCB unit expiration led to the discarding of collected UCB. For example, midwives 1 and 5 were not aware that UCB units could be stored for up to 72 hours after collection, she discarded units she had collected when UCB nurses were not able to process them. Due to this misunderstanding, she discarded units if they had been stored for 48 hours. Thus, in the future, it may be good practice to provide PHMD midwives with current training on UCBC procedures.

In Armstrong's (2018) study, one finding was that HCPs were not confident in their knowledge of UCBC and thus did not talk to parents about the procedure due to their lack of training. Conversely, general paediatricians with ten years or more of experience were significantly more likely to discuss the UCB topic with expected donors ( $p < 0.001$ ) than their younger colleagues. Approximately, 52.8% (250 out of 473 participants) of study participants cited the lack of UCBB knowledge as the main reason for not discussing the storage option with the expecting parents. In this study the findings were similar. UCB nurses were not provided with regular training on UCB procedures other than collection practice. As such, they may not have had the tools to appropriately discuss UCB with patients and therefore may mislead parents by providing them with misguided information. Moreover, the previous UCB team had self-assigned training on UCB procedure and were regularly informed about the UCB research field. This may have resulted in the previous UCB team being more confident about approaching parents as they were better equipped to relay information about UCBD.

Apart from recruiting more donors, training, and education on the UCB programme is important for HCPs to increase UCBC in general. Sward et al. (2019) conducted a hands-on training programme for obstetricians on UCB collection and found an increase in the volume of UCB units collected, and a reduction in wasted UCB units. UCB nurses and midwives in this

study were lacking in the required practical training on UCBC, which could have explained the poor collection rate.

An implication of this barrier is the emotional response that it elicited. The PHMD department often cited feelings of being unappreciated or disrespected in the demi-regularities. In Kim et al.'s (2015) scoping review on the conflict between HCP departments, they found that one of the key causes of conflict was the lack of mutual respect and differences in organisational structure. This understanding of the way the UCB programme works between the two hospitals is important in this study such that HCPs from each hospital have a better appreciation of each other's work. However, this lack of training and education on the UCB programme resulted in the PHMD team responding to perceived disrespect by distancing themselves from the UCB nurses. Further, Krugman et al. (2014) termed the reduced communication between groups as organisational silence, which ultimately can lead to reduced patient care.

### 6.3. Barriers: Ontological View

The proposed model shown in Figure 16 is based on the results of each stage of analysis. When constructing the model, the network of structures and events was focused on and their contribution to the central real accounting for the barriers of the programme. The figure recombines the main findings of each stage of analysis and reconstructs them according to the layer of reality they belong.

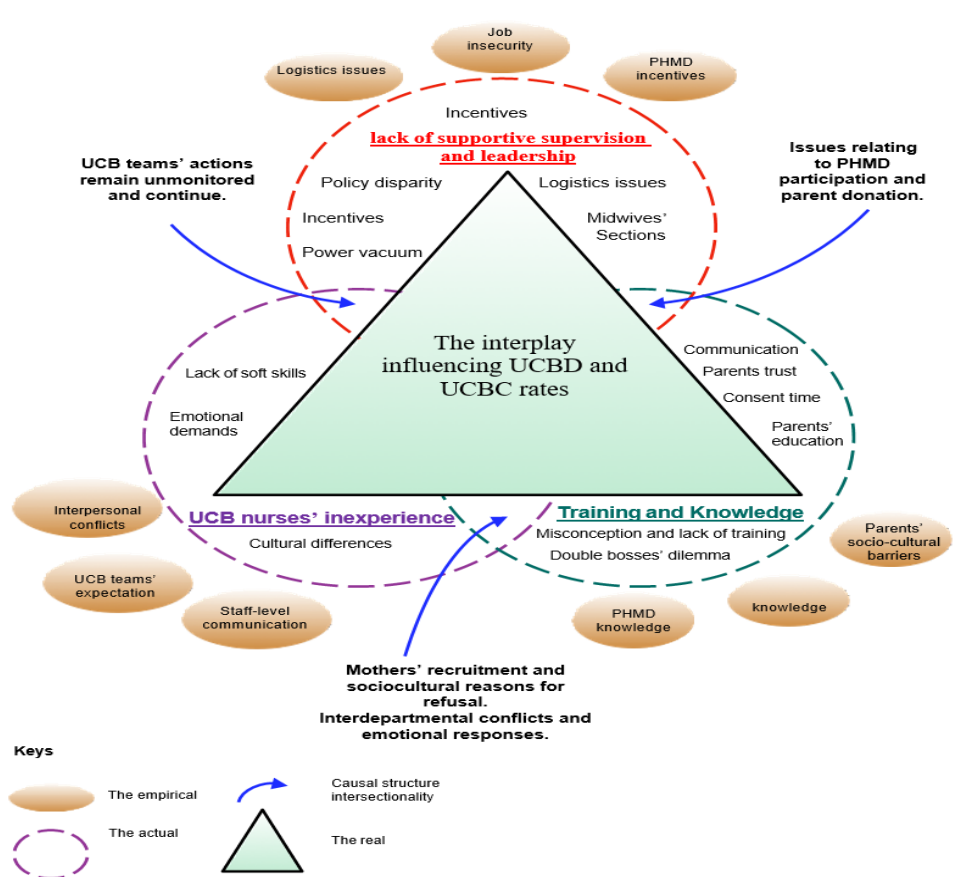


Figure 16. An ontological view of the three potential barriers to UCBD and UCBC in KSA.

The small brown bubbles on the periphery of the diagram represent the empirical events which are consequences of generative mechanisms. These events are assigned to their respective mechanisms. For example, on the top of the diagram, the little incentives on offer for PHMD participation is an empirical event that resulted from the lack of supportive supervision and leadership mechanism (indicated by the red dash-lined circle).

Next, three intersecting dash-lined circles, which are also the three mechanisms in this research, form the actual layer of reality. Within each of these mechanisms, several of their contributing structures are featured. For example, within the dash-lined circle UCB nurses' inexperience mechanism, interacting structures such as lack of soft skills and poor communication can be found, to portray the mechanism.

The three mechanisms overlap to represent the interactions they have with each other. The interplay between the mechanisms is illustrated by the blue arrow pointing to the area where the dash-lined circles intersect. Dash-lines are used to depict the porousness of the mechanism and that other structures are able to enter other mechanisms and impact on

empirical events (brown bubbles) that result from those causal structures. These mechanisms are related and interacted with each other to reveal other structures or events in the UCB programme. These interactions change according to the circumstances and events, as these interactions are constantly moving and shifting with the introduction of new structures or a change in the context of the programme. To show this manoeuvrability, the mechanisms overlap and are perforated to depict their unfixed nature as they can be affected by external elements.

For example, the lack of supportive supervision and leadership mechanism interacts with the UCB nurses' inexperience mechanism, to show that the UCB team's daily habits continued unsupported and thus a change in behaviour could not have been expected. When there was a lack of support provided to the UCB team, their soft skills had no means of developing through reinforcement or directed training.

The lack of supportive supervision and leadership, as well as training and knowledge mechanisms interacted with one another to give rise to a host of empirical events. An example of this was PHMD partners' knowledge of the programme's aims and interdepartmental managerial communication between PHMD leads and UCBBH lead. The training and knowledge and UCB nurses' inexperience mechanisms interacted with the lack of supportive supervision and leadership mechanism here. This provides explanation for the interdepartmental conflicts expressed by participants due to a lack of communication from the UCB department heads and the lack of social communication from the UCB nurses. This is seen by the lack of communication from the UCBBH department heads with the PHMD leads, but also on an informal level between the UCB nurses and PHMD midwives. Both were forms of communication, however they corresponded with different mechanisms. Although both were cases of miscommunication, they had different effects. PHMD leads felt affronted and ordered the midwives to not cooperate with the programme, whereas the PHMD midwives felt looked down upon due the lack of informal communication that they were accustomed to with the previous UCB team.

The model's central element (triangle) represents the real layer of reality for the barriers of the UCB programme. The research question explored why the UCBC rate was decreasing and the answer to this lies in the interplay between the three causal structures, which is the central thesis of this research. When these structures interact with one another, they resulted in the barriers. The three causal structures are all interconnected and manifest on the

empirical layer of reality as patterns and trends that were described by the participants in Chapter four.

The interplay between the mechanisms suggests a complex connection between them in the real layer of reality. This interplay had resulted in the reduction in the UCBC rate and thus, the issues within the UCB programme are systemic and not caused by an individual or a group of participants.

## 6.4. Systemic issue in the UCB programme

When a healthcare programme consistently fails to accomplish its intended aims or objectives because of defects in its conception, execution, or management, this is referred to as a systemic failure of the programme.

This research has revealed that several key functions are being impacted apart from the UCB rate of collection. The lack of supportive supervision and leadership suggests that there are issues with the management and leadership of the UCB programme, training and knowledge mechanism suggests that there are knowledge deficiencies for several key players in the UCB programme, including the parents, while the inexperience of UCB nurses suggests that there are political agendas that may have contributed to the issues and made it more difficult to resolve. These three mechanisms interact closely with each other as explained previously, impacting multiple functions of the UCB programme, in addition to the UCBC rates that this research is chiefly concerned with. This research revealed that the underpinning cause of the UCBC rate is not a single cause that can be isolated but a web of issues that are intricately connected by three interplaying mechanisms and shared structures. Hence, what was first conceived as a problem in the UCB programme outcome is actually a part of a wider systemic issue within the programme.

The UCB programme can be viewed as a system, wherein there are various infrastructures to support its various functions, including testing, collecting, donating etc. The complex problems experienced by the programme can be understood as issues within the UCB system. Issues in the UCB system include:

1. Differences in policies between UCBBH and PHMD.
2. Leadership that lacks clear direction and communication with programme partner.
3. Lack of supportive supervision of nurses working in PHMD.
4. Double bosses' dilemma of the UCB nurses.
5. Interpersonal issues between UCB staff and PHMD staff.



6. Logistical issues relating to transport and reporting procedures for UCB staff.
7. Manpower and skill level of UCB staff.
8. Availability of training and professional development of UCB members and PHMD partners.
9. Education on the programme for parents, UCB and PHMD staff and supervisors.
10. Superstition and religious concerns of parents.

The above issues are not isolated problems, nor are they the responsibility of a single party. Replacing the UCB nurses would not solve issues within the leadership and policy and replacing the leadership in the UCB would not resolve the religious concerns or the manpower problems.

Such systemic problems can also be seen in other systems within the healthcare setting. Research has revealed that healthcare initiatives which depend on contributions from the general population are susceptible to recurring failures for a number of reasons. For instance, Sontag-Padilla et al. (2012) noted one issue which makes it challenging to organise and sustain initiatives over the long term: the consistency of donations might be uncertain. Moreover, factors like media coverage and individual prejudices may have an impact on public donations, these may have an effect on how resources are allocated and also the success of initiatives (Prinja et al. 2015). Such elements may lead to poor healthcare initiatives and detrimental effects on the state of public health.

Studies conducted in the Middle East region have identified several factors that contribute to systemic failures in healthcare programmes. For example, a study by Alshammari et al. (2019) highlighted that inadequate funding, poor infrastructure, and a lack of trained healthcare professionals were common challenges faced by healthcare programmes in KSA. These factors led to a shortage of essential medical equipment and medication, resulting in a negative impact on patient health outcomes.

In addition, inadequate data management systems have been identified as a contributing factor to systemic failures in healthcare programmes in the Middle East. For instance, a study by Alshammari (2021) found that the lack of a unified electronic medical record system in KSA presented challenges in the management of patient data, which in turn had a negative impact on the quality of care provided.

Moreover, the lack of effective communication between healthcare providers and patients has also been identified as a factor contributing to systemic failures in healthcare

programmes. A study by Almutairi et al. (2015) found that language barriers and cultural differences often resulted in misunderstandings between healthcare providers and patients, leading to suboptimal care and negative health outcomes.

In conclusion, according to the literature cited above, systemic failures in healthcare programmes can have serious consequences for patients, healthcare providers, and the healthcare system as a whole. In this UCB programme, poor infrastructure, a lack of trained healthcare professionals, and ineffective communication were all factors which may have contributed to the systemic failure of this programme. Therefore, it is essential to address these issues through targeted interventions that focus on reconsidering the role of the UCB nurses and midwives in the programme, revising and clarifying areas of confusion through clearer policies, training for UCB nurses and midwives, education and timely consent-seeking procedures and better communication between UCBBH and PHMD and the wider public. These recommendations will be explored later in the chapter.

## 6.5. The Facilitators

The aim of the programme is a facilitator in itself. The UCB programme offers a service which aims to improve the quality of life for patients in need of UCB transplantation. UCB, in general when not collected, is considered a medical waste and through the UCB programme it is repurposed for life saving treatment.

Particularly in KSA, UCBD is understood to be a charitable act. Saudi Arabian culture values collectivism, where individuals believe they have a duty to be charitable towards others (Alqahtani 2018). This structure was seen repeatedly in all participant groups, not just mothers. Midwives who were aware of the benefits of UCB units for the wider population attempted to collect UCB, this mirrors the findings of Duffy et al. (2009). Parents who were aware of the programme previously were more inclined to donate.

The Hadith (sayings of the Prophet Muhammad) below denotes the importance of generosity towards others in Islam:

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***The Prophet said: "Every Muslim must give charity." They [the companions] said, "O Messenger of Allah, what if he cannot do that?" He, said, "Then let him help one who is in desperate need." He, said,***

*“Then let him do good, and refrain from doing evil, and that will be an act of charity on his part.” [Al-Bukhari and Muslim]*

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This facilitator however cannot be generalised to other countries. Interestingly, in Korea, Kim et al. (2015) found the converse to be true; parents were more inclined to store UCB for private use, this was explained as being due to the culture in Korea where family is of higher priority than the collective good of the wider society. In addition, Panasiti et al. (2020) noted that participants with the tendency to put family first were less likely to donate, whereas participants who were less connected to their family were more likely to be altruistic and donate UCB units. Katz et al. (2011) recognised that many parents were willing to donate CB with 59% stating it was for altruistic purposes, and a further 30% stating that donating CB was their duty.

However, it is important to note that while UCBD as an act of charity is a facilitator, this facilitator only works when parents are aware of the benefits of UCBD. As seen in the findings, parents with prior knowledge of the UCB programme before active labour were more determined to donate, despite the logistical barriers of donating off-site. Mothers interviewed were also more open to donation when informed about the benefits of UCBD. Unfortunately, knowledge about the UCB programme was a barrier. The charitable nature of UCBD, according to the findings, is also a facilitator, which encouraged PHMD midwives to collect. Some PHMD midwives continued to collect UCB despite the barriers because they were aware of the benefits of the programme for patients and UCBC was seen as a charitable act, an extension of UCBD.

This facilitator is limited by the knowledge of the UCB programme. Parents and midwives need to have a better understanding of the UCB programme in order for them to view UCBD and UCBC as a charitable act. Additionally, knowledge about the religious ruling on permissibility of UCBD is also important to encourage parents and midwives to take part in the programme. Knowledge about the benefits of UCBD and the UCB programme should not only be imparted at the hospital; there also needs to be a more proactive approach towards educating the general public about UCBD, including fathers and women in general, not just pregnant mothers who utilise the maternal services at the partner hospitals. This will be explained further below under the recommendations of this research.

## 6.6. Recommendations

The complex systemic issues experienced by the UCB programme indicate a need for reconsideration of the current UCB programme, the roles and responsibilities of those involved and the policies that hold the programme together. To identify the recommended changes, several UCB programmes and systems around the world have been considered, such as, the Human Tissue Authority (HTA), and Italian Bone Marrow Donor Registry (IBMDR). However, unique cultural practices and current infrastructural limitations in the UCB programme have made it difficult to follow practices in other countries.

Other Saudi Arabian blood and organ donation programmes have also been explored but they appear to have incongruent organisational structures compared to the UCB programme. Blood donation is not a national programme, instead, individual hospitals run their respective blood donation drives rather than collaborating with a central blood bank. Organ donation, while having more of a history than UCBD, remains rather insufficiently developed. A national organ donor registry was only announced in 2020 and there has been a history of donor organ shortage in the country (Wayne State University 2020).

To understand how the systemic issues in the UCB programme can be resolved, it is useful to consider the various infrastructures in place in the UCB programme and how they should change. The recommendations below have been developed based on the issues and barriers that have emerged from this CR analysis, as well as the best practices of UCB programmes globally.

### 6.6.1. UCB Programme, and roles of UCB and partner hospital staff members

The current UCB programme requires an overhaul. The roles of the UCB nurses and midwives, in particular, need to be redefined, and proper training and incentives should be in place for these new roles. Midwives were open to the idea of being solely responsible for the UCBC if they were appropriately incentivised. These incentives could take a number of forms such as training and professional development opportunities, days off or monetary incentives. There is some desire for UCB nurses to take on coordinator roles as well.

Below are some recommendations for the roles of the midwives and UCB nurses in this newly reconsidered UCB programme:

**1. The process of UCB should be streamlined and midwives made solely responsible for the collection of UCB units.**

This would cut down on the need for the UCB nurse to be present during such a busy time and would allow clearer boundaries to be drawn in their roles. Empowering midwives to be solely responsible for the UCBC is a practice used in Italy (IBMDR 2020).

**2. UCB nurses should refocus on recruitment and education of donor mothers and addressing the concerns of parents with regards to the UCB programme prior to the onset of labour.**

This way, the UCB nurses would be best placed in the outpatient department, parents could be referred to them during their regular visits and introduced to the programme. They could also attend appropriate education sessions with the UCB nurses. Consent should be sought at these referral sessions prior to labour and clearly indicated in the mother's hospital records, this would provide a clear indication of whether the midwives will need to collect UCB units during labour.

**3. UCB nurses should also take on a coordinator role.**

This would involve taking responsibility for logistics relating to the collected UCB units such as monitoring of UCB units collected by midwives, setting and evaluating collection targets and the transportation of units to the laboratory. UCB nurse coordinators (previously UCB nurses) should be responsible for the training of midwives on their expanded role, the day-to-day issues relating to the collection of UCB units at their allocated hospital and cascading policy and updates on collection outcomes from UCBBH to their allocated hospital staff. This would require UCB nurse coordinators to take on a more senior managerial role than their current station in the UCB programme and necessitates the recruitment of more senior and experienced nurses to fill the role, preferably with experience in oncology, haematology, immunology where UCB units are used.

These clearly defined roles may reduce areas for interpersonal conflict, there would be less overlap of responsibilities between the UCB nurse coordinators and midwives. UCB nurse coordinators work predominantly in the outpatient clinic whilst midwives work on the wards. Cultural, generational and educational differences would be harder to resolve as they are inherent social structures which exist both inside and outside the context of this research. However, in recruiting more senior nurses for a predominantly managerial role as UCB nurse

coordinators, it is likely that these nurses would be experienced in deescalating situations, culturally sensitive practices, appropriate communication skills and professional behaviour.

Figure 17 depicts the journey of a mother from outpatient to labour and the proposed various responsibilities of the staff members in the UCB programme.

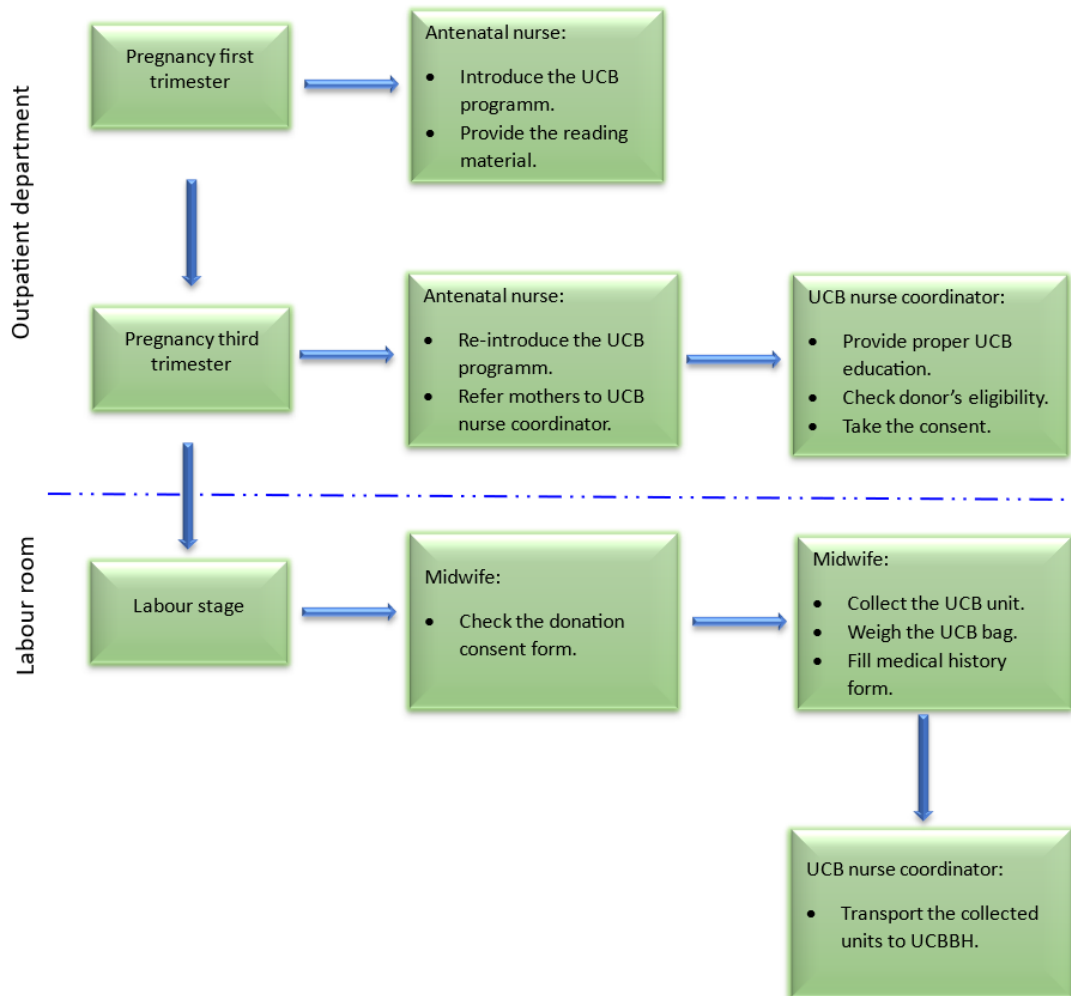


Figure 17. The journey of a mother from outpatient to labour and the proposed responsibilities of the staff members in the UCB programme.

At the first trimester antenatal routine checkup, the antenatal nurse should introduce the UCB programme and process and provide reading materials. In the third trimester antenatal care nurses should reintroduce the UCB programme to the parents especially for mothers who have elected for caesarean section. This is in keeping with Grieco et al.'s (2018) study, which recommended that the UCB programme should be introduced in the first trimester as a form of introduction to the idea of UCBD, then revisited formally in the third trimester. Their

research has shown that of all the six study groups, the group that followed this protocol was more likely to achieve donation of UCB units. During the third trimester, antenatal nurses would refer parents to the UCB coordinator for more in-depth education on the programme, patient health medical history, eligibility and consent.

In the labour room and in the operating theatre, midwives would check the UCBD consent forms to ensure that the form is signed and has appropriate witness information before performing the collection procedure. For planned caesarean sections, collection of UCB in the operating theatre would be ideal since UCBC should be conducted under sterile technique. Similar to the current practice in the PHMD, the midwife who performs the collection will weigh and label the UCB units and note down the relevant information for the lab. This information includes recording the medical record number of the mother and the time of collection etc. UCB coordinators will then collect and transport the donated units back to UCBBH for testing.

## 6.6.2. Policy

The findings demonstrated that there is some confusion with regard to infection control and contamination policies where the UCBBH policy is different from that of PHMD. Below are some policy recommendations for consideration:

**1. UCBBH blood collection procedures need to be adhered to during UCBC.**

This would resolve confusion where UCBBH protocols may conflict with practices in the partner hospitals, such as the number times the collection site need to be cleaned. This is also necessary due to the requirements of the UCB quality and consistency across all the partner hospitals, and this must be made clear during the midwives' UCBC training.

**2. All training requirements needs to be clearly explicated in the policy.**

While training is already part of the policy, the current UCB programme policy does not cover training on obtaining consent from parents. Findings of this research demonstrated that consent was sought at inappropriate times and that nurses needed more training in this area. The IBMDR (which also covers UCBD) has policy wording that captures this training requirement (IBMDR 2020, p.18):

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***13.2. The recruitment must be done by trained professionals of IBMDR Donor Recruitment Centers qualified and experienced in management activities including education, consenting,***

*counselling, confidentiality, and medical screening. The training and experience of these individuals must be documented.*

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Similarly, the HTA in the UK has clearly stated this in their standards (HTA 2007, p.3):

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**1.C3.** *Staff involved in seeking consent receive training and support in the implications and essential requirements of taking consent.*

**2.a.** *Staff involved in obtaining consent are provided with training on how to take informed consent in accordance with the requirements of the HT Act 2004 and Code of Practice on Consent.*

**3.b.** *Training records are kept demonstrating attendance at training on consent.*

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Such policies must be in place in the UCB programme in KSA to ensure that the UCB coordinators are appropriately trained in taking consent from donors.

**3. There should be more promotion of the UCB programme to the general public.**

The education and awareness of the UCB programme should not only be the responsibility of UCB coordinators, more effort needs to be made by the UCBB to promote the programme to the general public to correct misunderstanding on religious rulings and to dispel superstitions about UCBD. In Italy (IBMDR 2020, p.9),

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*The RR (Regional Registry) promotes awareness and provides consultancy and training on the HPC (Haematopoietic Progenitor Cell) donation and transplantation to the health personnel.*

*The RR promotes activities to inform and educate the regional community on HPC donation, focusing its efforts on specific settings (schools, communities etc.) in collaboration with local volunteer associations and with its collaborators.*

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Such policies, if included in the Saudi Arabian UCB programme policy, would empower the UCBB to promote the programme to the public. There is also room to



make use of social media platforms such as Snapchat and Twitter to engage younger parents. This is something that has been regularly utilised in KSA to promote public health campaigns such as breastfeeding, women's health, and breast cancer awareness, targeting Saudi Arabian women and families (AlSadrah 2021). Support from the MOH is required and the national UCBB initiative should be publicised through MOH facilities and channels in order to expand and sustain the national inventory of UCB banks.

**4. Policy documentation should clearly state the need for regular communication between UCBBH and partner hospitals.**

There is a need for formal communication between UCBBH and PHMD and documentation of such communication. This would include annual reports, monthly UCBC reports and UCBC requirements, so that information can be cascaded down to the PHMD managers, midwives and UCB coordinators based in the partner hospitals. Such communication can be formalised through policy additions such as in IBMDR (2020, p. 40):

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*20.15.26. Every form and written communication must be signed by the competent UCB bank supervisor or director and the IBMDR must receive a copy of every communication.*

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Informally, there will need to be regular site visits and meetings with partner hospitals, this would ensure stronger relationships are established and maintained. This will also ensure a physical presence of the UCBB at the partner hospitals, ownership of the UCB programme and consistent oversight of the programme by the UCBB.

### 6.6.3. Leadership

Finally, below are the commendations of the leaders of the UCB programme to assist the changes to the UCB programme suggested earlier:

**1. UCB inventory size targets need to be clearly set.**

UCB leadership needs to determine the required or targeted UCB inventory size to cover the community needs whilst focusing on high quality UCB units and the establishment of a minimum inventory goal for the forthcoming year. These inventory targets for the programme should then be conveyed to the partner

hospitals. There must be more transparency and clarity in the programme partnerships for all parties involved. Currently, intended inventory sizes, programme goals, chain of command and promotion activities are not clear and some parties are not aware of them.

**2. More partnerships with other collection sites need to be established.**

The leadership should establish more connections and partnerships with neighbouring maternity hospitals that satisfy the collection criteria, such as an appropriate annual birth rate, prenatal care system, and diverse ethnic backgrounds. This is to expand collection sites and increase the rate of collection.

**3. Spatial requirements, in light of the earlier recommendations, need to be negotiated.**

As part of the partnership agreement, there should be appropriate space allocation at the outpatient department at the partner hospitals in order to conduct patient education sessions, collect consent, address any questions patients may have and to evaluate donors. This is similar to the requirements of the Italian UCBB partnerships (IBMDR 2020, p.12):

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**7.1 ...CCs (collection centres) must:**

- have appropriate spaces dedicated to donor evaluation and collection procedure.*
  - have a location which guarantee immediate donor support in case of emergency (emergency labour)*
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A room would need to be made available in the labour department, solely for the storage of UCB units and paperwork, separate from the lounge for UCB nurse coordinators.

**4. UCB nurse coordinators should be given more autonomy and unnecessary reporting procedures should be removed.**

To prevent unnecessary logistical issues and micromanagement, the UCB nurse coordinators should report straight to the partner hospital maternity department

head nurse in the morning and work remotely at the collection centre hospital. UCB nurse coordinators should not micromanaged.

**5. UCB nurse coordinators should be made aware of their career progression.**

When UCB nurse coordinators are hired, they need to be made aware of their future career development. Promotional opportunities should be stated clearly in their contract.

## 6.7. Study Strengths and Limitations

Throughout the process, the steps of analysis and the multitude of questions answered along the way led to this thesis having many strengths. The rigour and depth of this research are its primary strengths. Analysis required deep thought and reflection (Appendix I) and involved many steps that incorporated testing (albeit theoretical) and incorporation of philosophical assumptions and definitions. One way in which this thesis was rigorous was the manner in which CR was incorporated. I critically engaged with the CR literature, questioning myself constantly on how well the theories applied in this research helped to explain the findings. For example, some CR scholars such as Wynn and Williams (2012) had argued for the separation of the abduction and retroduction in the analysis whilst other scholars such as Danermark et al. (2002) had recommended these two steps should be conducted simultaneously. Danermark et al. (2002) method was applied in this thesis, separating abduction and retroduction may have resulted in some structures being lost within the process. Combining these processes enabled me to achieve a greater appreciation of the connection between the various layers of ontology, hence affording a more complex understanding of the phenomenon.

Being an oncology nurse and UCB donor myself there was a risk of researcher bias, this could have affected the way in which the data was interpreted. To guard against this, I used TDF to structure the interview questions, to guide the initial coding of the data and arrive at the demi-regularities. CR was used beyond this point to guide the abduction and retroduction process. Understanding the CR paradigm has made me aware of my own bias and how that may impact the analysis. The use of CR has ensured that my personal experiences of the UCB programme and UCBD did not influence the way I distilled the barriers and facilitators, keeping the focus on the data from the research participants. Using CR analysis, the barriers and facilitators were developed through an in depth understanding of the various mechanisms within the UCB programme and an understanding of how the structures and

mechanisms had interacted. The frequent use of direct quotes from participants, and triangulation using policy documents and observation notes, ensured that the analysis was well grounded by the data and not influenced by researcher bias. By constantly referring to the research question, I was also able to ensure that the analysis was not distorted by my own bias.

Additionally, the use of CR to academically analyse public healthcare programmes in KSA is still in its infancy, however this thesis uses CR in a clear guided manner. This thesis can provide some methodological guidance to future researchers who are interested in using CR to explore healthcare programmes.

Epistemic fallacy was a study limitation in this study. In this context, the understanding of the realities of the phenomenon were limited to what was collected as data. In the data analysis during the abduction stage, structures that were explicated were informed by the interviews conducted, field note observations and document analysis. There is a possibility that that some structures which were not captured by the data collection methods (perhaps due to the reticence of the interview participants), hence remained hidden. However, in this research, the number of interviews conducted explained the phenomenon and this was corroborated and triangulated with field note observations and document analyses. Steps were taken in this research to ensure that data collection was as comprehensive as reasonably possible, considering the time allocated for the data collection and the permissions that were granted by the study site. The findings of this research also demonstrated a complex picture of the phenomenon, and the study objectives were appropriately answered.

Fathers were not recruited to the study as participants and the lack of data from fathers was a limitation. Due to the restrictions at the hospital, recruitment of fathers was not possible and there were issues with finding a large enough space at the hospital for data collection. Data from the fathers could have potentially provided a different perspective of some of the issues or barriers raised in the research such as male dominance.

## 6.8. Discussion summary

In this chapter, the findings from the analysis were discussed using CR theory and in context with the findings of the research. The mechanisms and causal structures that were explicated in Chapter five were further explored using the CR stratified ontology. The three layers of reality, in the context of the UCB programme, were explained, defined, and explored. This

analysis resulted in the emergence of the barriers that affected the programme and that had resulted in the decline in the UCBC rate.

The results of this thesis showed that the programme's UCBC rate was decreasing due to the interplay between three causal structures at the heart of the mechanisms. Three barriers were identified:

1. Lack of supportive supervision and leadership: management issues including leadership, policies, and oversight of the UCB programme limited the success of the UCB programme.
2. Inexperienced UCB nurses: The hiring of inexperienced nurses resulted in some difficulties in ensuring that nurses were sufficiently equipped with the appropriate skills to fulfil their role in the programme.
3. Lack of knowledge about the UCB programme: Parents' lack of understanding of the programme resulted in poor UCBD. For the UCB nurses and midwives, their lack of understanding had an impact on their effectiveness in recruiting donors and collecting UCB units.

UCBD as an altruistic act fits well within the Islamic teachings. The altruistic nature of the act of collecting and donating UCB units should be something to focus on when recruiting donors and encouraging midwives to support the programme.

The complex nature of the mechanisms and general problems in the programme suggest that the issues are systemic and appear to cause problems to various aspects of the programme. The key recommendation of this thesis was that midwives should be charged with the job of collecting UCB units while the UCB nurses should function as UCB coordinators and focus on recruiting and educating mothers. This would streamline the UCB programme, drive UCBD and recruitment. Broader infrastructures, internal and external to the UCB programme, such as public health campaigns through the MoH to promote the programme and a unified Saudi Arabian UCB programme, are recommended to ensure the success of UCB programmes.

## Chapter 7. Conclusion

### 7.1. The study

A CR study was undertaken to theorise an explanation for the potential barriers and facilitators which contributed to the decline in UCBD and UCBC rate in the Kingdom of Saudi Arabia (KSA). Participants' perspectives were gathered through 37 in-depth interviews with pregnant mothers, UCB nurses, midwives, antenatal team members, and policymakers, as well as field observation and document review. This was followed by a rigorous CR analysis to reveal the potential causal structures that resulted in the observed barriers and facilitators to UCBD and UCBC.

This research found some contributing factors which had caused the decline in UCBD and UCBC. Changes in UCB market demand and criteria resulted in a shift in focus from quantity of UCB units to quality of the UCB units collected, while demand for UCB units fell due to new alternative treatment. Poor knowledge and awareness were also identified amongst the healthcare workers and mothers. UCBD comes with some sociocultural issues surrounding UCBD and its acceptability within the KSA culture and religion. Within the UCB programme there are various managerial issues such as poor communication, management of UCB nurses, logistics and lack of incentives. Interpersonal conflict between the UCB nurses and PHMD staff has also led to a breakdown in the partnership within the UCB programme.

### 7.2. Study Recommendations

This study recommends changes to how the UCB programme is being managed. Midwives should be tasked with the collection of UCB units while UCB nurses should work as coordinators between the UCBBH and partner hospitals. UCB coordinators should also focus on educating parents and securing consent for UCBD. To support this, there should also be clearer policies surround the training of UCB staff and midwives, incentives for midwives to motivate UCBC and formal communication between UCBBH and partner hospitals. UCB programme leaders also need a clearer understanding of the programme targets, more transparency surrounding career progression when hiring UCB coordinators and negotiate appropriate spatial requirements within their partnership agreement for the education of potential donors, storage of UCB units and for their staff.

### 7.3. Contribution to Knowledge

This thesis' contribution to knowledge is the conceptual model (Figure 16, p. 216) that shows that the programme's UCBC rate was decreasing due to the interplay between three causal structures. At the heart of this thesis, is the interplay of the three barriers, and how their interaction had led to the empirical events seen in the demi-regularities. Also, this was the first ever study to explore factors associated with UCB programme in KSA. This research has made practical recommendations for various stakeholders.

In previous research, there was a lack of clarity about how CR can be employed, how abduction and retroduction is conducted and how a researcher arrives at the generative mechanisms from the observed events. In this research, I attempted to show how this was achieved and how a researcher can arrive at the causal structures through CR analysis. More about this research journey and the challenges of implementing CR are in Appendix I.

### 7.4. Future research

There is a need for an action research study to design and evaluate the effectiveness of an interventional programme using the guidelines of Medical Research Council for complex intervention. Based on the barriers and recommendations of this PhD study, this action research study could explore, implement and evaluate the proposed recommendations to investigate how effectively they overcame the barriers. While causal structures were identified, there needs to be more empirical research to test these causal structures and how they affect the UCBD and UCBC rates.

### 7.5. Conclusion

Decades ago, UCB was recognised as a valuable source of stem cells that were widely used in the field of stem cell transplantation, this resulted in a significant achievement in oncology and haematology fields. For some haematology diseases such as leukaemia, transplant clinicians prefer to use alternative sources of stem cells such as Haploidentical and bone marrow registries. Although, for some diseases, such as metabolic disorders, UCB transplants are still the only therapeutic option.

UCBB is an ever-changing field. Over time, the demand in UCB has shifted, and thus it is difficult to predict whether saved units will be suitable for future uses. In this research context, the priority for UCBB is deciding how to build a UCB bank infrastructure with

continued maintenance. This is because the country's healthcare system requires access to a basic stockpile – regardless of the demand shifting and fluctuations. The study findings and recommendations can act as a starting point to build that necessary infrastructure as discussed in Chapter six.

At this stage in UCBB in KSA, it is crucial to make the necessary changes swiftly, to avoid the breakdown of the programme. The UCB programme should not rely on the actions of especially motivated individuals, it should be built to last and motivate individuals in the programme to take engage.



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## Appendix A: Screenshots of some of the databases utilized to conduct the study's literature review.

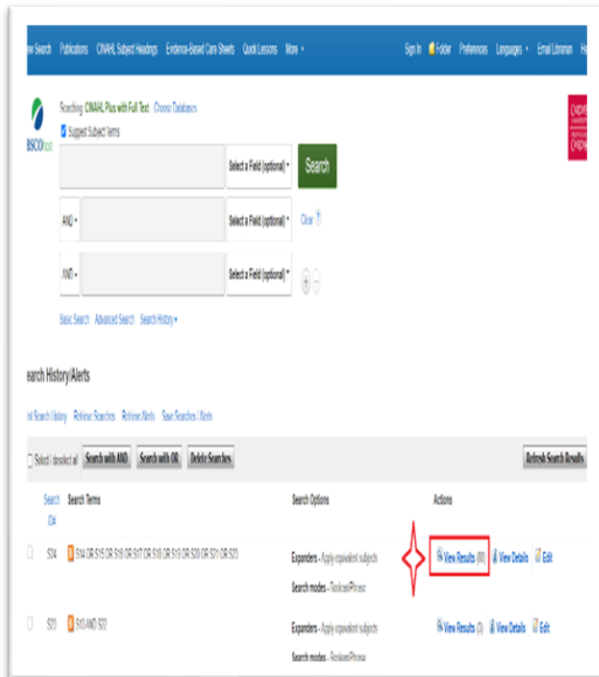


Figure 19. CINAHL Data-Base Search: 88 literatures, After title filtering = 17.

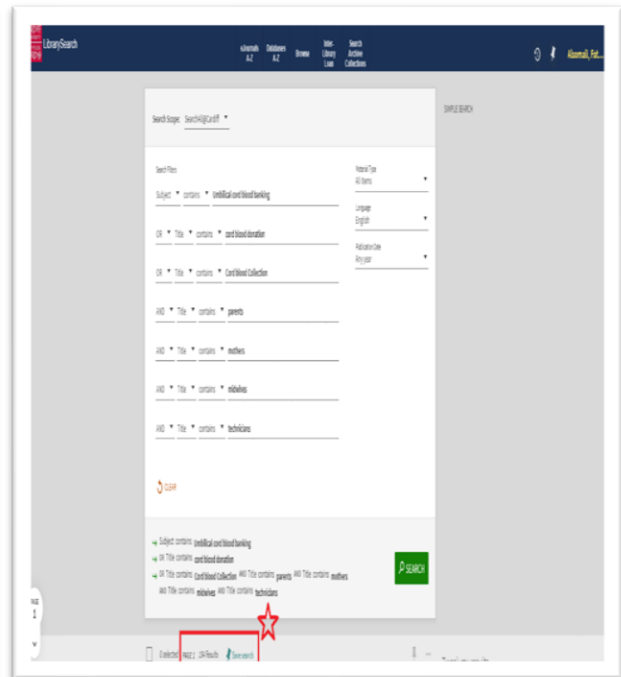


Figure 18. Cardiff University Library: 154 literatures after title filtering = 102

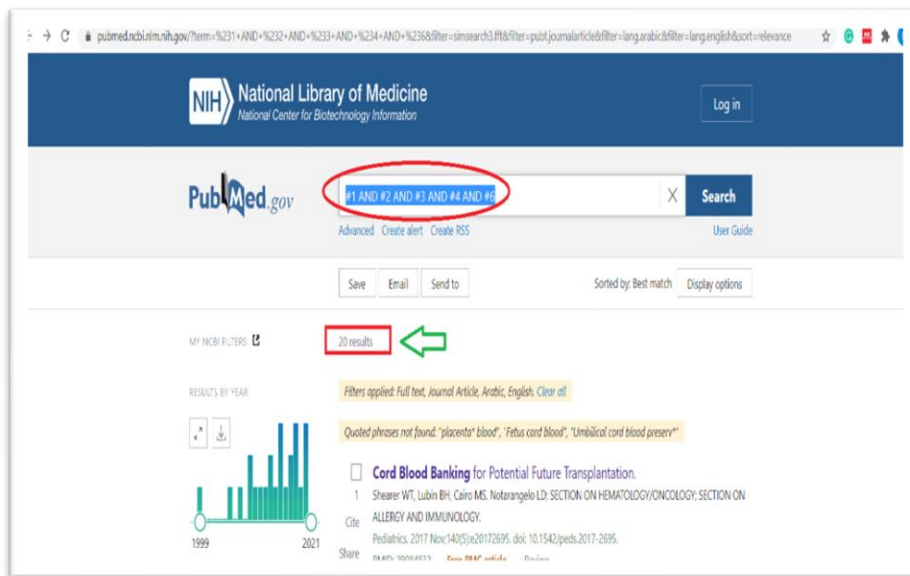


Figure 20. Pub Med Search: 20 Articles, then after title filtering = 9.

## Appendix B: Ethical approvals

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*

08 November 2018

Fathiyah Al Somali  
School of Healthcare Science  
Cardiff

Dear Fathiyah


**A study on the Partnership Programme of a Public Umbilical Cord Blood Bank in the Kingdom of Saudi Arabia: A Critical Realist Approach**


The School's Research Ethics Committee considered your research proposal. The decision of the Committee is that your work should:

**Pass –and that you proceed with your Research in collaboration with your supervisor.**

Please note that if there are any subsequent major amendments to the project made following this approval you will be required to submit a revised proposal form. You are advised to contact me if this situation arises. In addition, in line with the University requirements, the project will be monitored on an annual basis by the Committee and an annual monitoring form will be despatched to you in approximately 11 months' time. If the project is completed before this time, you should contact me to obtain a form for completion. Please do not hesitate to contact me if you have any questions.

Yours sincerely

  
Research Administration Manager

Cc: 

Cardiff University  
Eastgate House  
13<sup>th</sup> Floor  
35 – 43 Newport Road  
Cardiff CF24 0AB

Tel Ffon: +44 (0)29 20 688559  
Email E-bost [HCAREEthics@cardiff.ac.uk](mailto:HCAREEthics@cardiff.ac.uk)

Prifysgol Caerdydd  
13<sup>th</sup> Llawr  
Ty Eastgate  
35 – 43 Heol Casnewydd  
Caerdydd CF24 0

Cardiff University  
PRIFYSGOL  
CAERDYDD

Cardiff University is a registered charity, no. 1136855.  
Mae Prifysgol Caerdydd yg elusen gofrestredig, rhif 1136855

Figure 21. Cardiff University ethical approval letter.



Gen. Org. الإدارة العامة

**RESEARCH ETHICS COMMITTEE**

MBC: , Ext: 24528 , Fax: 27894

**INTERNAL MEMO**

**TO:** Nursing Recruitment Coordinator  
Nursing Recruitment & Retention Section - Riyadh

**DATE:** 8 Jumada Al Thani 1440  
13 February 2019

**FROM:** CoChairman  
Research Ethics Committee

**REF:** C380/469/40

**SUBJECT:** **PROJECT # 2191 046**

The above-referenced proposal was reviewed expedited by the Research Ethics Committee (REC) on 12 February 2019. It is my pleasure to inform you that the REC has recommended the Proposal, Participant Information Sheet, Interview Questionnaires and the Waiver of Signed Consent Form for approval as submitted; and I would like to take this opportunity to congratulate you on behalf of the Research Advisory Council.


Please note that this study is approved with a Waiver of Signed Consent Form and the process of verbal consent should be documented in the Medical records/Investigator file of enrolled subjects. This should clearly specify:

1. The research subject' acceptance to participate in the study;
2. The project's RAC number;
3. The date the verbal consent was obtained;
4. The name and signature of the principal investigator/ delegate.

Please be informed that in conducting this proposal, the Investigators are required to abide by the rules and regulations of the Government of Saudi Arabia, KFSH&RC, and the RAC. Further, you are required to submit a Progress/ Final Report by 12 January 2020; so it can be reviewed by the Committees without lapse of approval. The approval of this proposal will automatically be suspended 12 February 2020, pending the acceptance of the Report. You also need to notify the ORA as soon as possible in the case of any amendments to the project, termination of the study, any event or new information that may affect the benefit/risk ratio of the project.

Figure 22. UCBBH ethical approval letter.

المملكة العربية السعودية  
وزارة الصحة  
الوكالة المساعدة للتخطيط والتنمية المؤسسي  
الإدارة العامة للبحوث والدراسات

  
**وزارة الصحة**  
 Ministry of Health

وزارة الصحة  
03-12-2018 25-03-1440  
1440-680331  
1440-680331

الموضوع، بحث الطالب/ة/فتحية الصومالي.

**سعادة/ مدير عام الشؤون الصحية بمنطقة الرياض**  
**ص. لسعادة /مدير مستشفى**

المحترم  
المحترم

**السلام عليكم ورحمة الله وبركاته،،،**

إشارة إلى موضوع الطالب/ة/ فتحية عمر بن يوسف الصومالي، المبتعث من جامعة الإمام عبدالرحمن الفيصل بالدمام لدراسة الدكتوراة في تخصص " التمريض " بكلية العلوم الصحية (قسم التمريض) بجامعة كارديف بالمملكة المتحدة، رقم السجل المدني (١٠٠٢٤٨٨٢٠١)، وعنوان البحث،

نحيطكم علماً بأن الطالب/ة/ قد استوفت كافة المستندات المطلوبة وتمت مراجعتها من قبل اللجان المعنية بالإدارة العامة للبحوث والدراسات ولجنة الأخلاقيات بوزارة الصحة، وتمت الموافقة على تسهيل مهمة إجراء هذا البحث، وحيث أن الطالب/ة/ ستنفذ جزء من دراستها في مستشفى بمنطقة الرياض.

وعليه، نأمل من سعادتكم التفضل بالإطلاع والإيعاز لمن يلزم بتسهيل مهمتها بعد موافقة الجهات المختصة لديكم، لجمع البيانات اللازمة بما يضمن أن لا يكون هناك أي تأثير على خدمة المراجعين خلال قيامها بمهامها بحثها، مع العلم بأن وزارة الصحة تضمن حقوقها في نتائج هذا البحث من خلال إتفاقية المشاركة في البيانات والتي تم توقيعها بين الطالب/ة/ والإدارة العامة للبحوث والدراسات.

**وتفضلوا بقبول خالص تحياتي،،،**

مرفق مستندات وملخص المقترح البحثي،،،،،

**مدير عام الإدارة العامة للبحوث والدراسات**

Figure 23. Saudi Ministry of Health ethical approval letter.

# Appendix C: Participants' information sheets and consents forms

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## **Healthcare professional's information sheet**

**Study Title:** A study on the Partnership Programme of a Public Umbilical Cord Blood Bank in the Kingdom of Saudi Arabia: A Critical Realist Approach

### **Study Information:**

You are being invited to take part in a study conducted on understanding the factors affecting the current level of umbilical cord blood donation. This information sheet will explain the purpose of the study and what is involved if you do decide to partake. If any of the information provided below is not clear or you require further information, please feel free to ask. This study will not involve any vulnerable or underage people with consent being sought from all participating adults.

### **Purpose of the study:**

Research has found that the level of umbilical cord blood donated within Saudi Arabia is insufficient to meet the current demands especially in relation to essential treatment for specific blood disorder diseases such as Thalassaemia and leukaemia.

Umbilical Cord Blood (UCB) donation has the potential to save lives through the treatment of diseases such as leukaemia, lymphomas, beta-thalassaemia, and other blood-related disorders. The current research being conducted is in the field of stem cell science, a requirement within my PhD degree. The aim of the project is to gain an insight and understanding of the different perspectives of UCB from key stakeholders within the procedure (mothers, healthcare professionals, and policy makers). Thus, providing greater insight into the motivations for donating from the perspective of expectant mothers but also the role of healthcare workers in promoting UCB banking.

### **Why have I been recommended?**

You are currently employed within a one of few partnership hospitals that provide umbilical cord blood transplantation services and your assistance might provide an insight into the factors, which you believe effect blood cord donation. You are now receiving this invitation to determine whether you are willing to contribute to this study to improve umbilical cord blood donation. Please be aware that any medical related information has not been passed on or will at any point be necessary for taking part.

It is also key to note that participation is entirely voluntary and whether you choose to contribute or not it have no effect on your career or the medical care in which you provide.

### **What will taking part involve?**

If you do agree to participate in the study you will be required to complete an initial questionnaire form, which gathers demographic data to describe participants. The data will remain anonymous with the use of pseudonyms unique to each participant in order to ensure complete anonymity. Following this you will be invited to a one to one interview with the student researcher to discuss your understanding of umbilical cord banking and what you believe may facilitate or prevent donation or storage. This interview will last no more than 45 minutes and will be arranged in Al-Yamamah hospital at a suitable time for you, ideally before or after a shift and then you may resume with your usual routine.



minutes and will be arranged in Al-Yamamah hospital at a suitable time for you, ideally before or after a shift and then you may resume with your usual routine.

There will be no physical aspect to this study and will all be conducted verbally. To fully participate you would be required to complete both components and if you have any issues regarding this please do feel free to get in touch.

It is important to clarify that the student researcher will carry out some observation within the maternity department, during the data collection period. The student researcher will observe the participant's activities and behaviours in relation to UCB donation and collection, which might help to understand the factors that could affect UCB banking.

**Will you contact me in the future?**

Following the completion of this study you will be informed of the results and may be asked to contribute to development of the interventional programme based upon the barriers learnt from this study.

**Are there any disadvantages or risks involved when taking part?**

The level of risk associated within partaking in this study is very minimal especially given that the study doesn't require anything other than verbal discussions to be held with no medical intervention at any point in the study. The assessment method for this study is a one to one interview and a focus group session that will have minimal risk associated. Please note that in choosing to contribute to this study, care has been taken to ensure it poses no psychological or mental health risk to you. The questions being asked during the study have been carefully compiled and if you do feel at any point unable to answer please do not hesitate to say so.

With respect to the interviews, care will be taken to ensure that no conflict occurs which could effect your external environments and identities will be concealed where possible.

**What are the benefits for taking part?**

This research may help to provide a better understanding of different perspectives surrounding umbilical cord donation with emphasis on any barriers faced by families preventing or discouraging donation. This may also assist with improving the level of care and health service provided to patients in need of umbilical cord blood units. As a token of appreciation, you will be gifted with vouchers upon completion of this study. Each participant will receive a voucher equal to 10GP (50 Saudi Riyal) in form of two cups of coffee for two persons.

**Will my involvement be kept confidential?**

All data obtained from the research conducted will be kept with the strictest adherence to UK data privacy laws and held for a maximum of 5 years. In order to ensure complete anonymity each participants key identifiable information will only be available to the student researcher and will never be published with the data analysed. You do reserve the right to withdraw any data provided following your interview up until the data is analysed and published.

**What information will be recorded and how will this be kept?**

All the information collected during the course of this study will be strictly confidential available only to the student researcher, and subsequently to the academic supervisors after the



anonymization of the participants' identities. Data will be captured using an encrypted audio recorder, password protected with access only available to the student researcher, being deleted following their transcription. In order to ensure transcripts of recordings are unidentifiable, the data will be anonymised. After the completion of the transcribing process, the collected data will be translated with the help of professional translators. The identities of the participants will be concealed and kept confidential. The data will be kept using online storage protected by passwords and encryption along with other relevant security procedures.

**Who is organising this research?**

This research is conducted as a component of a postgraduate doctoral degree in conjunction with Cardiff University, King Faisal Specialist Hospital and Al-Yamamah hospital in the KSA.

**What if something goes wrong?**

This study requires for participants to complete an in person interview and attend a focus group discussion session there is very little which could go wrong. If you have a concern about any aspect of this study, you should ask to speak to the researcher who will do their best to answer your questions using the contact information below. If you remain unhappy and wish to complain formally, you can do this by contacting the School of Healthcare Sciences Director of Research Governance

**What happens now?**

If you do decide to join this research please contact the student researcher on the contact details shown below. This is a pioneering opportunity to improve the successes of umbilical cord blood donation.

- **Name:** Fathiyyah Alsomali
- **Email Address:**
- **Phone number:**

If further information regarding the current umbilical cord donation or banking process is required please visit the KFSHRC stem cells Donation website: (<https://www.kfshrc.edu.sa/en/home/giving/stemcell>) to gather a more in depth understanding.



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School of Healthcare Sciences  
HEALTHCARE PROFESSIONAL CONSENT FORM

IRAS ID:

Participant Identification Number for this trial:

Title of Project:

Name of Researcher: Fathiyah Alsomali

Please initial box

1. I confirm that I have read the information sheet dated..... (Version.....) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.
3. I agree to be audio-recorded during the study and understand that data collected will be encrypted and password protected to protect my identity.
4. I am aware and understand that the information gathered will undergo transcription and translation processes. Nevertheless, my status as a participant will be anonymized and maintained in strict confidentiality, and therefore, I give my consent.
5. I confirm that data from the study can be used in the final report and other academic publications. I understand that these will be used anonymously and that no individual respondent will be identified in such report.
6. I give consent for the use of verbatim-anonymised quotes in publications and conference presentations.
7. I understand that the findings and potentially secondary analysis of the findings and associated data from the study may be presented at conference and in scientific journals. I understand that these will be used anonymously and that no individual respondent will be identified in such report.
8. I understand that individuals from Cardiff University, Al-Yamamah and King Faisal Specialist Hospital's may look at relevant sections of the data collected provided my identity is concealed and it is relevant to my taking part in this study.
9. I am aware and understand that the information collected will compose the research for this PhD study and may also be used in future work on the same subject.
10. I understand that the student researcher will need to observe my activities and behaviours inside the work field during the data collection period thus, I give my consent for this purpose.
11. I agree to take part in the above study.

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

## Research about umbilical cord blood donation



Ref: ANDREI WOLICKE/SCIENCE PHOTO LIBRARY

PIS (V2, 29/10/2018)

1

etc. This study doesn't include any physical aspects and is all completed during one interview session.

It is important to clarify that the student researcher will carry out some observation within the maternity department, during the data collection period. The student researcher will observe the participant's activities and behaviours in relation to UCB donation and collection, which might help to understand the factors that could affect UCB banking.

### **Will you contact me in the future?**

You will not be contacted for a follow up session once you attend the interview session.

### **Are there any disadvantages or risks involved when taking part?**

The level of risk involved if you do choose to join this study is very minimal and will not include anything physical or mentally challenging.

### **What are the benefits for taking part?**

Joining this research may help us to understand the views of expectant mothers towards umbilical cord blood donation. As a mother, you are in a unique position to assist with this by giving your perspective on the improvement of the level of care and health services provided to patients in need of umbilical cord blood. Also, as a small token of appreciation for joining the study, you will be gifted with a voucher at the end of the interview. Each participant will receive a voucher equal to 10GP (50 Saudi Riyal) in form of two cups of coffee for two persons.

### **Will my involvement be kept confidential?**

Taking part in this study will not change or affect the care or treatment you receive in any way. The responses you provide during the interviews will be kept confidential and data will be kept on record for a maximum of 5 years as per regulations within the UK Data privacy laws. If you choose to take part, your answers will remain anonymous and provided with pseudonyms so you are not personally identifiable, with answers only being available to the student researcher and academic supervisor. If, at any point, you decide you no longer want to take part in this study, you can ask to be removed at any point before the data is published.

### **What information will be recorded and how will this be kept?**

You will be audio recorded during your interview so that the student researcher can analyse the answers given properly. All the information collected during the course of this study will be strictly confidential, available only to the student researcher, and subsequently to the academic supervisors after the anonymization of the participants' identities. In order to ensure transcripts of recordings are unidentifiable, the data will be anonymised. After the completion of the transcribing process, the collected data will be translated with the help of professional translators. The identities of the participants will be concealed and kept confidential. The data will be kept using online storage protected by passwords and encryption along with other relevant security procedures. The recordings made of each interview will be securely destroyed once they are written up. The written data will be password protected with access only available to the student researcher, stored using online storage.

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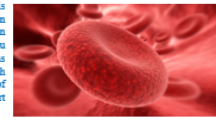
3

### **Study Title:**

Umbilical cord blood donation in maternity department

### **Study Information:**

As an expectant mother you are being invited to join this study on understanding umbilical cord blood donation within Saudi Arabia. This information sheet will explain the purpose of this study and what is required if you choose to take part. If any of the information remains unclear please contact the student researcher, Fathyiyah Alsomali, using the information provided at the end of this pamphlet. It is important to also note that taking part is entirely voluntary.



Ref: Red Blood Cell Disorders and Diseases/istockphoto.com

### **Purpose of the study:**

The umbilical cord serves as a lifeline between the mother and child during pregnancy providing nutrients to the baby. During childbirth the umbilical cord is separated from the child and mother once the child is delivered, leaving some nutritional blood in the cord. The detached cord tends to be discarded but contains potentially life-saving cells. These cells can be used in blood transplants to treat blood cancer (such as leukemia) as well as other disorders. The blood found in the umbilical cord can be stored for several years to preserve its potential for treating diseases which is useful and beneficial to people that may require this blood in the future.

This research may help us to understand what expectant mothers know about umbilical blood donation and what efforts are being made in Saudi Arabia to improve collection of cord blood. This study will focus on the opinions of expectant mothers and healthcare professionals working in this area.

### **Why have I been recommended?**

A nurse within the maternity unit has recommended you for this study as you are nearing the final trimester of your pregnancy. As an expectant mother your contribution is very valuable to understanding umbilical cord blood donation in Saudi Arabia. This study is entirely voluntary and will be scheduled at a suitable time for you within the maternity hospital you currently attend for appointments. Joining in will not change the maternity care you receive and if you do decide to join any information you do pass on will be kept confidential.

### **What will taking part involve?**

Joining this study would involve being interviewed in a private room at Al Yamamah Maternity Hospital, which should last approximately 45 minutes. The questions you will be asked will give you the chance to explain your understanding of umbilical cord blood donation and also provide insight into your experience donating if you have done this previously. The study will be done ideally during a waiting period in between appointments. You will also be asked to complete a short questionnaire to include information such as your age group, marital status

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### **Who is organizing this research?**

This study is being conducted by Cardiff University in the UK with the help of King Faisal Specialist Hospital and Al-Yamamah Hospital in Saudi Arabia.

### **What if something goes wrong?**

This research involves being interviewed and we think any risks of taking part are very low. If you do have any concerns during the study, please do speak to the student researcher who will assist you and answer any questions you might have. If you are still unhappy and would like to put in a formal complaint, you can do so by contacting:

School of Healthcare Sciences: |

Email:

Telephone:

In the highly unlikely event that something does go wrong and you are harmed during this study, you will have the grounds to take legal action.

### **What happens now?**

If you have any further questions about joining the study, the student researcher's contact details are provided below for you to reach out to and get involved:

- Name: Fathyiyah Alsomali
- Email Address:
- Phone number:

If you would also like to know more about umbilical cord blood donation, please visit the King Faisal Hospital and Research Centre website:

<https://www.kfahrc.edu.sa/en/home/visiting/stemcell>



Ref: Janine Dopants Photography  
Newborn Baby Close up Newborn Feet Close Up

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4



**CARDIFF UNIVERSITY**  
**School of Healthcare Sciences**  
**MOTHERS CONSENT FORM**

**IRAS ID:**

**Participant Identification Number for this trial:**

**Title of Project:**

**Name of Researcher:** Fathiyyah Alsomali

**Please initial box**

1. I confirm that I have read the information sheet dated..... (version.....) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected
3. I agree to be audio-recorded during the study and understand that data collected will be encrypted and password protected to protect my identity.
4. I am aware and understand that the information gathered will undergo transcription and translation processes. Nevertheless, my status as a participant will be anonymized and maintained in strict confidentiality, and therefore, I give my consent.
5. I confirm that data from the study can be used in the final report and other academic publications. I understand that these will be used anonymously and that no individual respondent will be identified in such report.
6. I understand that individuals from Cardiff University, Al-Yamamah and King Faisal Specialist Hospital's may look at relevant sections of the data collected provided my identity is concealed and it is relevant to my taking part in this study.
7. I am aware and understand that the information collected will inform this PhD study and may also be used in future work on the same subject.
8. I understand that the student researcher will need to observe my activities and behaviours inside the work field during the data collection period thus, I give my consent for this purpose.
9. I agree to take part in the above study.

Name of Participant	Date	Signature
Name of Person	Date	Signature
Taking consent		

## Appendix D: Midwives' UCBC sheet during the data collecting period.

Table 19. Collection Facility: Primary Hospital Maternity Department (PHMD) Period:  
21/01/2019 till 27/05/2019.

<i>Week no.</i>	<i>Number of collected units</i>	<i>Weight in Gram</i>	<i>Collection Type</i>	<i>Collected By</i>
<i>Week 2 and 3</i>	Zero collection			
<i>Week 4</i>	1	124	In utero	Midwife 2
<i>Week 5 till 11</i>	Zero collection			
<i>Week 12</i>	2	106	In utero	Midwife 2
		153	In utero	Midwife 4
<i>Week 13</i>	Zero collection			
<i>Week 14</i>	2	96	In utero	Midwife 3
<i>Week 15</i>	1	101	In utero	Midwife 2
<i>Week 16 till 19</i>	Zero collection			
<b><i>Total</i></b>	6 Units			

# Appendix E: Semi-Structured Interview Questions

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### Questions for mothers' interviews

The aim of the interview with the mothers is to understand the barriers and facilitators to the donation of their cord blood. This interview will focus on the Capabilities, Opportunities and Motivations of the mothers, as supported by the COM-B model.

1. Capabilities
  - a. Physical and psychological
    - i. Knowledge and understanding of CB donation that facilitates or restricts their ability to donate
2. Opportunities
  - a. Social and Physical
    - i. Social and physical barriers and facilitators to CB donation such as stigma, religious restriction, opportunities to donate offered by HCP during their labour or any part of their care etc.
3. Motivation
  - a. Automatic and Reflective
    - i. The key internal/personal drivers behind CB donation such as the desire to help others in need (altruistic or deontological ethical), possible monetary motivation for the mothers.

**In-depth Questions:**

1. Now that you read the PES, did anything else come to your mind while reading the Participant information sheet?
  - a. Tell me about your experience when you had your last baby?
  - b. Did you donate any cord blood then? If yes, why did you decide to do that / if not why?
    - i. If yes, what encouraged you to donate your baby's UCB
    - ii. If no, what prevented you to donate?
    - iii. If yes, did you slightly least about UCB, what would encouraged you to donate your baby's UCB in future
    - iv. Would knowing that your donation has used encourage you to donate again?
4. Some people know about UCB banking and some people don't. Can you tell me what do you know about UCB banking?
  - a. Uses or benefits of UCB
  - b. Drawings
  - c. Differences between public and private banking of UCB
  - d. Available banking options in Saudi Arabia

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### Questions for antenatal team interviews

The aim of the interview with the antenatal team is to understand the barriers and facilitators to the collection of cord blood from mothers. This interview will focus on the Capabilities, Opportunities and Motivations of the antenatal team, as supported by the COM-B model.

1. Capabilities
  - a. Physical and psychological
    - i. The provision of appropriate training and knowledge about cord blood collection
2. Opportunities
  - a. Social and Physical
    - i. Opportunities within the organisation to facilitate the collection of cord blood such as being allocated time to educate mothers about CB donation, CB collection as part of their job description etc.
    - ii. Social context or societal perspective of CB collection and donation, does it restrict or facilitate the HCPs to have conversations about donation with their patients/mothers
3. Motivation
  - a. Automatic and Reflective
    - i. The key internal/personal drivers behind CB collection such as monetary incentives, or cost savings for organisation or UCB.

**In-depth Questions:**

1. Now that you read the PES, did anything else come to your mind while reading the Participant information sheet?
  - a. Have you received any training about UCB banking
 

<i>If yes</i> <ul style="list-style-type: none"> <li>o When was the last training or education?</li> <li>o How often do you go for training or education about UCB?</li> </ul> What kind of information you received? <ul style="list-style-type: none"> <li>o E.g. Lectures, hands on practice, on line</li> </ul>	<i>If no</i> Why were you not trained to do so? <ul style="list-style-type: none"> <li>o Opportunity... why?</li> <li>o No time... why?</li> <li>o Not interested... why?</li> <li>o Any other thing</li> </ul>
---	---
3. Could you tell me anything you know about UCB banking?
  - a. Uses or benefits of UCB
  - b. Drawings
  - c. Differences between public and private banking of UCB

2

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 Email: [UCBS@100@cardiff.ac.uk](mailto:UCBS@100@cardiff.ac.uk)

### Questions for mothers' interviews

4. What do you think is understood to sign the donation forms and consent?
  - a. One mother sign it alone?
  - b. It should be a shared decision (mother and father)
5. Are you aware if there is any policy or procedure for UCB in your hospital?
 

<i>If yes</i> <ul style="list-style-type: none"> <li>o Can you tell me what do you know about it?</li> <li>o How does this entire process conducted?</li> <li>o Who is responsible for each step of the process?</li> <li>o How do you follow up if the mother donated UCB (e.g. mother's medical record, system update)</li> </ul>	<i>If no</i> <ul style="list-style-type: none"> <li>o How do you think hospital policies may encourage you to recruit mothers for donation?</li> <li>o How do you think this policy can affect your work?</li> </ul>
---	--
6. Have you ever recruited mothers to donate their babies' UCB?
 

<i>If yes</i> <ul style="list-style-type: none"> <li>o What motivated you?</li> <li>o How do you usually recruit mothers and prepare them to donate UCB?</li> <li>o Who do you think is the responsible healthcare professional to recruit pregnant mothers for such procedure?</li> <li>o What is your specific role in consent recruitment procedure (i.e. educate parents, sign the consent, complete history form)</li> <li>o How do you persuade mothers to donate their umbilical blood cord?</li> <li>o Would it be easy or difficult for you to recruit mothers for UCB collection? Why?</li> </ul>	<i>If no</i> <ul style="list-style-type: none"> <li>o What is holding you back?</li> <li>o Who do you think is responsible to recruit mothers about this procedure?</li> <li>o What would motivate you to recruit mothers?</li> </ul>
---	---

4

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### Questions for midwives' interviews

The aim of the interview with the midwives is to understand the barriers and facilitators to the collection of cord blood. This interview will focus on the Capabilities, Opportunities and Motivations of the midwives, as supported by the COM-B model.

1. Capabilities
  - a. Physical and psychological
    - i. The provision of appropriate training and knowledge about cord blood collection
2. Opportunities
  - a. Social and Physical
    - i. Opportunities within the organisation to facilitate the collection of cord blood such as being allocated time to educate mothers about CB donation, CB collection as part of their job description etc.
    - ii. Social context or societal perspective of CB collection and donation, does it restrict or facilitate the HCPs to have conversations about donation with their patients/mothers
3. Motivation
  - a. Automatic and Reflective
    - i. The key internal/personal drivers behind CB collection such as monetary incentives, or cost savings for organisation or UCB.

**In-depth Questions:**

1. Now that you read the PES, did anything else come to your mind while reading the Participant information sheet?
  - a. What is the period between educating mothers and asking them for consent
  - b. When do you place the donation consent and form? E.g. in the system, patient's record? Where exactly in the record?
  - c. How do you follow up if the mother decided to donate?
7. Have you ever had any incident where a mother request to donate UCB voluntarily?
 

<i>If yes</i> <ul style="list-style-type: none"> <li>o What have you done in relation to that?</li> <li>o Consent but the common details of UCB</li> <li>o Provided her with brochures or information sheets for her to read</li> <li>o Refused her to continue</li> <li>o One to one education</li> </ul>	<i>If no</i> <ul style="list-style-type: none"> <li>o How would you respond if a mother ask to donate UCB?</li> </ul>
--	---
8. Do you feel that you have the necessary resources and appropriate physical context to perform donor recruitment?
  - a. Paper work,
  - b. Training,
  - c. Location and space,
  - d. Complacency of consent process,
  - e. or others
9. What do you think will happen if you recruit the pregnant mothers? In other words, what are the impacts of doing or not doing this procedure?
  - a. Can you tell me what do you think about UCB banking?
  - b. What is your personal opinion about UCB banking?
  - c. Do you think that your personal opinion may affect your motivation or interest to recruit mothers for UCB banking?
11. Are there any emotional factors (e.g. stress) that can potentially influence you if the procedure is done? Could you please explain?
  - a. What are your personal opinions about UCB banking?
  - b. Do you think that your personal opinion may affect your motivation or interest to recruit mothers for UCB banking?

5

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### Questions for midwives' interviews

12. Do you think your colleagues may influence you to recruit mothers? Explain how?
  - a. Yes
  - b. No
13. Do you have any suggestions to enhance or encourage UCB banking?
  - a. Yes
  - b. No

6



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3. Could you tell me anything you know about UCB banking?

- o Uses or benefits of UCB
- o Disadvantages
- o Differences between public and private banking of UCB
- o Available banking options in health facilities
- o How do the procedures perform? (Data status or extra status)
- o Transportation and storage of the UCB unit
- o Most appropriate pregnancy terms to receive information from and sign the consent forms
- o Recipients of donated UCB
- o Recipient preserved UCB
- o Associated Cost

4. Who do you think is authorized to sign the donation forms and consents?

- o Can mother sign alone?
- o It should be a shared decision (mother and father)

5. Are you aware if there is any policy or procedure for UCB in your hospital?

**If yes,**

- o Can you tell me what you know about it?
- o How does the entire process conducted?
- o Who is responsible for each step of the process?
- o How do you document the mother donation? (E.g. in her medical records or the hospital system?)
- o If not, how can you make this better?

**If not,**

- o Do you think hospital policies will encourage you to recruit mothers for donation?
- o How do you think this policy will affect your work?

6. Have you ever collected UCB units?

**If yes,**

- o Where have you done in relation to that?
- o Called the UCB bank staff to send someone to collect the UCB unit?
- o Gave her the consent form to sign and then you collected the unit by yourself?

**If not,**

- o How would you respond if a mother ask to donate UCB?

7. Have you ever had any incident where a mother request to donate UCB voluntarily?

**If yes,**

- o How do you feel about it?
- o How do you feel about the incident?
- o How do you feel about the mother's decision?
- o How do you feel about the incident?

**If not,**

- o How would you respond if a mother ask to donate UCB?

8. Do you feel that you have the necessary resources and appropriate physical context to perform donor recruitment?

**If yes,**

- o What resources do you have?
- o How do you feel about the resources?
- o How do you feel about the physical context?

**If not,**

- o How would you respond if a mother ask to donate UCB?

9. What do you think will happen if you recruit the pregnant mothers? In other words, what are the impacts of doing or not doing this procedure?

10. Can you tell me what do you think about UCB banking?

- o What is your personal opinion about UCB banking?
- o Do you think that your personal opinion may affect your motivation or interest to recruit mothers for UCB banking?

11. Are there any external factors (e.g. stress) that can potentially influence you if the procedure is done? Could you please explain?

12. Do you think your colleagues may influence you to recruit mothers? Explain how?

13. Do you have any suggestions to enhance or encourage UCB banking?

**Questions for policy makers Focus Groups**

The aim of the interview with the policy makers is to understand the barriers and facilitators to the collection of cord blood from mothers. This interview will focus on the Capabilities, Opportunities and Motivations of the policy makers, as supported by the COM-B model.

1. Capabilities
  - a. Physical and psychological
    - i. The provision of appropriate training and knowledge about cord blood collection for the UCB
    - ii. Provision of information about CB donation for mothers
2. Opportunities
  - a. Social and Physical
    - i. Providing HCP with the opportunity to recruit, educate mothers, making it part of their job description.
    - ii. Providing mothers with the opportunity to opt in or opt out of the donation procedure, changing societal perspectives of CB donation through public education.
3. Motivation
  - a. Automatic and Reflective
    - i. Providing motivation for HCP and mothers to collect and donate, monetary incentives, public education.

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**A. UCB bank at UCBBI:**

1. Now that you read the FIS, did anything else come to your mind while reading the Participants information sheet?

2. Having this UCB collection partnership with PHND, can you talk more about it?

- o When did you start this partnership with PHND?
- o What did you agree on?
- o Terms of agreements
- o Role of UCB bank staff in relation to UCB collection and banking
- o Any policies to manage this partnership
- o Your expectations for this program
- o What is the current rate?
- o What is the potential target of how much umbilical cord blood is required per year or per month? (i.e. the future bank size)
- o How do you usually inform PHND about your monthly or yearly target?

3. Why was partnership with PHND made?

- o The aim of this partnership

4. Do you think that the current level of UCB bank collection is currently sufficient to cover the public needs?

- o If yes, can you explain how that is sufficient?
- o If not, can you tell me why?

5. How do you currently educate or inform mothers about UCB donation?

- o Who recruit pregnant mothers i.e. your own staff or PHND staff?
- o When do you provide mothers with this information, specifically at what stage in their pregnancy?
- o Has this approach been successful?
- o Any obstacles facing you currently to recruit mothers?

6. How do you currently collect the UCB units?

- o Explain the current process for UCB collection
- o Who collect the units for you i.e. your own staff or PHND staff?
- o Has this approach been successful?
- o Any obstacles facing you currently to collect the UCB units

7. Who do you think is responsible for this procedure?

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8. What efforts have been taken so far to increase collection rates?

- o Training and education sessions to mothers and maternal team
- o Recruit more staff to do increase banking rate
- o Do you offer any motivation
- o Public education
- o Media

9. What can motivate PHND staff to perform this procedure?

- o Monetary incentive
- o International training

10. Is there a policy regarding guidelines on UCB?

- o If yes, can I see them?
- o If not, why not?

**B. PHND:**

1. Now that you read the FIS, did anything else come to your mind while reading the Participants information sheet?

2. Having this UCB collection partnership with PHND, can you tell more about it?

- o When did you start this partnership with UCBBI?
- o What did you agree on?
- o Role of PHND in relation to UCB collection and banking
- o Terms of agreements
- o Any policies to manage this partnership
- o The potential target
- o The current rate
- o How do you usually get informed about the monthly or yearly target of this partnership?

3. Do you think that the current level of UCB bank collection is currently sufficient to cover the public needs?

- o If yes, can you explain how that is sufficient?
- o If not, can you tell me why?

4. How do you currently educate or inform mothers about UCB donation?

- o Who recruit pregnant mothers i.e. your own staff or UCB staff?

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5. How do you currently collect the UCB units?

- o Explain the current process for UCB collection
- o Who collect the units for you i.e. UCBBI staff or PHND staff?
- o Has this approach been successful?
- o Any obstacles facing the staff currently to collect the UCB units

6. Who do you think is responsible for this procedure?

- o E.g. monetary incentive
- o E.g. international training

7. How can you motivate PHND staff to perform this procedure?

- o E.g. monetary incentive
- o E.g. international training

8. What can motivate your staff to perform UCB collection?

- o When do you provide mothers with this information, specifically at what stage in their pregnancy?
- o Has this approach been successful?
- o Any obstacles facing you currently to recruit mothers?

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**COM-B model interpretation on the context of this study**

Component	HCP	Mothers	Policy Makers
<b>Physical Capability</b> Physical strength, skill or stamina	Skills to recruit and collect the UCB units	Physical health of mother that allow her to donate a healthy UCB unit.	Policies and guideline that inform the process of donation and collection. These will affect Physical and Psychological Capabilities of the HCP and Mothers
<b>Psychological Capability</b> Knowledge or psychological strength, skill or stamina	Understanding and knowledge of UCB collection and banking	Awareness about UCB	E.g. provision of training for antenatal nurses or using media to improve public awareness regarding UCB donation
<b>Physical Opportunity</b> Opportunity afforded by the environment, time, locations, resources	Facilities to recruit mothers to donate and UCB collection e.g. collection kit, workload, or time	Offered the opportunity to donate	Providing facilities, the environment to the HCP to collect CB
<b>Social Opportunity</b> Opportunity afforded by social factors, cultural norms, resources	Understanding social context of donation and collection process, and whether it affects their ability to talk about it or do it social cues	Social stigma/ religion, or cultural opportunity that might affect their desire to donate	Providing access to information, religious permission for mothers
<b>Automatic Motivation</b> Automatic brain processes e.g. desires, impulses, inhibitions	Emotional motivation to collect UCB o Empathy to save the lives of patients in need for these units. It's could be related to spiritual beliefs or community o Previous experience with sick family member or friend	Emotional impact to donate a part of your body to save lives service o Self-satisfaction o Previous experience with sick family member or friend in need for stem cells transplantation.	Monetary incentive, or emphasize the importance of community service (HCP)  Highlighting the impact of CB donation e.g. Helping someone in need through publicity and public education (for mothers)

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Component	HCP	Mothers	Policy Makers
<b>Reflective Motivation</b> Reflective brain processes and evaluations	Thinking deeper about implication of UCB collection e.g. o Cutting the cost of import UCB unit from \$49000 to \$8000. o Time saving to find a match donor for sick patients on the stem cells transplantation list. o Acting as a Role model for other colleagues o Incentive or obligation as a part of my duty	Thinking deeper about UCB donation e.g. spiritual values and community service It's could be also monetary motivation e.g. I will give my babies UCB for a certain amount of money	

## Appendix F: Unstructured non-participant observations guide

In this study observation, a combination of Spradley's (1980) and Merriam's (1998) dimensions of descriptive observations were used. Merriam (1988) approach is similar to Spradley (1980) and merging the two guides would add further layers to the observations obtained in this study. Merriam (1988) developed an observation guide in which a compilation of various elements is compiled into field notes. The physical environment constitutes as the first element, which involves observing surroundings and describing the context. The next element is the description of the participants, in great detail. MERRIAM (1980) then records the interactions and activities that happen in the observed setting, ensuring a noting on the frequency and duration of the events, and noting all the other subtle factors. Factors noted such as informal, unplanned activities. MERRIAM also recommends observing other elements, such conversation matter between individuals, the initiator of said conversation and other minor processes that make up a conversation. Other elements MERRIAM (1980) recommends observing are the researcher's position, behaviour and reflections of the researcher of their particular circumstance. The recommendations were useful for the directing observations for this study, where the main focus were behaviour and events with a minimal level of interactions between participants (Watson et al, 2010). The guides were mainly used to systematically record surroundings, individuals, emotions, and accomplishments. The use of the guides increased feasibility of ensuring focus was maintained on the collection of data (Watson et al, 2010).

### **Observation dimension**

- Space and physical environment: Observe the location's surrounds. Provide a written description of the environment such as the rooms, corridors, waiting areas, furniture...etc.
- Goal: describe what it is that the participants are trying to achieve. In addition, researchers must try to determine the actions they really want to observe.
- Time: be aware of the sequence of events and the time period in which they occurred
- Actors: the names and relevant details of the people involved, describes the actors in detail
- Activities, Acts, and events Keep a record of the activities and interactions that take place in the surrounding area. Keep track of how often and for how long the contacts



and activities occur. Consider casual, unscheduled activities, symbolic meanings, nonverbal communication, physical hints, and what should have occurred but has not yet.

- Feelings Describe your emotions in relation to any witnessed occurrences. This is required to reduce the researcher's bias.
- This point was from Merriam's (1998)
- Content: Observe the content of the conversation, who speaks, who replies, and what occurs during the silences. Be mindful of the researcher's influence on the observers, as well as how the participants react in the presence of the researcher. What are their reactions? What is the researcher supposed to say?

Table 20. Spradley's Dimension of Observations (1980) Version.

Dimension of observation	Notes
<b>Space and physical environment:</b> observing the surroundings of the setting and providing a written description of the context	
<b>Actors:</b> describes the actors in detail	
<b>Activities:</b> records the activities and interactions that occur in the setting	
<b>Objects:</b>	
<b>Acts:</b>	
<b>Events:</b>	
<b>Time:</b> frequency and duration of those activities/interactions and other subtle factors such as informal, unplanned activities, symbolic meanings, nonverbal communication, physical clues, and what should happen that has not happened.	
<b>Goals:</b>	
<b>Feelings:</b>	

Table 21. Merriam (1988) developed an observation guide.

Observational elements	Note
Physical environment: to observe the surroundings of the setting and providing a written description of the context	
Participants' description:	
Activities and interactions:	
Frequency and duration (of those activities or interactions):	
Other subtle factors such as: <ul style="list-style-type: none"> <li>• Informal/unplanned activities,</li> <li>• Symbolic meanings</li> <li>• Nonverbal communication,</li> <li>• Physical clues,</li> </ul> What should happen that has not happened	

Table 22. Example of one day of field note observations.

Observation elements	Notes
<p><i>Space and physical environment</i></p> <p>Observing the surroundings of the setting and providing a written description of the context</p>	<p>Drown a map for the data collection setting</p>
<p><i>Event one:</i></p>	<p><b>Date:</b>18/03/2019</p> <p>09:07 AM:</p> <p><b>Goal:</b></p> <p>To see any activities or actions related to the UCBC or UCBD.</p> <p><b>Actors:</b></p> <ul style="list-style-type: none"> <li>• Pregnant mother</li> <li>• Midwives</li> <li>• Obstetricians</li> <li>• Charge nurse</li> <li>• Nursery nurse</li> </ul> <p><b>PHMD Staff:</b> There were five midwives on duty, four of them are assigned to delivery rooms while the fifth one was assigned to the nursery area. The charge nurse is busy on the phone with the admission office arranging for new admissions from ER and antenatal ward. One resident doctor was around to assist a primipara mother to give birth.</p> <p><b>Patients:</b> A total of 6/8 beds are occupied, four of them are in active labour with cervical dilated between 4 to 9 CM.</p> <p><b>Nursery:</b> only one new-born in the nursery at that time.</p> <p><b>Actions, activities, contents:</b></p> <p>It is <b>09:07 AM:</b> now. I finally arrived at the study setting after a long traffic jam on the way. I entered from the emergency door wearing my hospital ID. I passed by the main reception then I took the right way walking through a long corridor where the delivery ward located at the end of that corridor. I used the code to open the ward door. I immediately saw the nursing station where the charge nurse was busy on the phone arranging for an upcoming admission from the ER. And two midwives were busy</p>

on the computers. I greeted the staff on the nursing station... they greet me back in a very friendly way. I went to the staff lounge room (which is on the left side of the station) to wear my lab coat and start the work.

**At 09:23 AM** I greeted the staff again; I had a quick friendly chat with the charge nurse. Then I started a quick round to see what was going on.

The first delivery was completed at **09:35**. That was in bed two.

**Mother one:**

- Age..., and number of births.
- Gestational age: ....
- Medical history ....
- A registered case in PHMD hospital for regular prenatal check-up

**Baby**

- Baby's sex
- Initial assessment
- Apgar score
- weight
- Umbilical cord characteristics
  - length
  - colour
  - numbers of vein and arteries
  - rotund, dark grey colour, glistening, and moist. Two arteries and one vein
  - meconium stains or not
  - odder
- The obstetrician was around and managed the labour process.
- The midwife cut the UCB and clamped it within the first minute, showed the baby to the mother, wrapped the baby with a blanket, and delivered the baby to the nursery personnel.
- 25 minutes later, the placenta was delivered. Examined by the midwife to make sure it's intact and that nothing has been left behind in the uterus, then discarded it together with the umbilical cord. ***Nothing was mentioned about the UCB donation or collection.***

***Feelings:***

***The Mother:***

	<ul style="list-style-type: none"> <li>• was panicking as this was her first experience of giving birth. She was not following the instructions and she was closing her legs. The midwife started shouting at her and called the obstetrician for help.</li> <li>• Mother was not happy with the midwifery care.       <ul style="list-style-type: none"> <li>- Said “I will make a formal complaint against you. No one has the right to shout at me. We are in a hospital not in jail.”</li> <li>- body language (angry face: inward eyebrows and squeezed them together in a wrinkle. lifted her chin)</li> </ul> </li> </ul> <p><b>The midwife:</b></p> <ul style="list-style-type: none"> <li>• She tried to explain the situation to the mother that she is taking care of another ongoing active labour, but the mother was very angry and crying.</li> <li>• The midwife said “<i>I am trying my best here, but if you are not satisfied, go ahead please and write your complaint. Maybe this time the management will understand what we are going through</i>”) then she left the mother and started writing in the patient file.</li> <li>• Body language (negative and stressed)       <ul style="list-style-type: none"> <li>- The midwife shrugged, (raising her shoulders for a moment and loosening it) accompanied by a longed face and both palms were opened. <i>This gesture in our culture means: that there is nothing to hide, or there is nothing more to be done.</i></li> <li>- The midwife turned her body away from the crying mother.</li> <li>- Eyes downcast, little contact</li> <li>- start writing her notes in the patient medical file.</li> </ul> </li> </ul> <p><b>Researcher:</b></p> <ul style="list-style-type: none"> <li>• I think the midwife should’ve controlled her voice tone particularly, that the mother was primigravida.</li> <li>• I felt sorry as well for the midwife who was trying very hard to do her work.</li> <li>• I think the midwife did not mean to be rude to the mother, she had a heavy workload at that time but still she has no right to shout at her.</li> </ul>
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	<ul style="list-style-type: none"> <li>I felt little bit frustrated as this is week number 7 and none of the midwives performed UCB collection or even mentioned it. Interpretation of this: my present might influence their practice. (NB: use journal reflection.</li> </ul>
<p><i>Event two:</i></p>	<p><b>Actors:</b></p> <ul style="list-style-type: none"> <li>Pregnant mother</li> <li>Midwives</li> <li>Obstetricians</li> <li>UCB nurse</li> <li>Nursery nurse</li> </ul> <p><b>Actions, activities, contents:</b></p> <p><b>09:41 AM</b></p> <ul style="list-style-type: none"> <li>Mother one: falls sleep and the midwife resumed the documentation in order to transfer the mother to the postpartum ward after an hour.</li> <li>I went back to the nursing station to observe further interaction among the staff.</li> </ul> <p><b>09:44 AM:</b></p> <p>A new admission from ER has arrived with cervical dilated of 6 CM.</p> <p>A total of 7 patients are now in the ward.</p> <p><b>09:53 AM:</b></p> <p>The charge nurse and the head nurse were at the nursing station. The obstetrician arrived to assess the new admission and went directly to room 7. A few minutes later (<b>around 09:58</b>), the UCB nurse arrived. UCB nurse ‘good morning” no eye contact at all she said that in a very weak tone and walked immediately to the UCB collection room. No response or greeting back from the charge nurse or the midwives.</p> <p><b>10:27 AM:</b></p> <p>The mother in bed four gave birth.</p> <p><b>Mother in bed 5:</b></p> <ul style="list-style-type: none"> <li>Age..., and number of births.</li> <li>Gestational age: ....</li> <li>Medical history ....</li> <li>A registered case in PHMD hospital for regular prenatal check-up</li> </ul> <p><b>Baby</b></p> <ul style="list-style-type: none"> <li>Baby’s sex</li> <li>Initial assessment</li> </ul>

	<ul style="list-style-type: none"> <li>• Apgar score</li> <li>• weight</li> <li>• Umbilical cord characteristics <ul style="list-style-type: none"> <li>- length</li> <li>- colour</li> <li>- numbers of vein and arteries</li> <li>- rotund, dark grey colour, glistening, and moist. Two arteries and one vein</li> <li>- meconium stains or not</li> <li>- odder</li> </ul> </li> </ul> <p><b>Midwife:</b></p> <ul style="list-style-type: none"> <li>• The midwife manages the labour process.</li> <li>• No Episiotomy was performed.</li> <li>• The UCB team nurse was still in the UCB collection room. The room was closed.</li> <li>• The midwife clamped the cord then cut it, showed the baby to the mother, covered the baby blanket, and passed the baby to the nursery staff. She did not inform the UCB team nurse about the delivery.</li> <li>• 20 minutes later, the Placenta was out and examined by the midwife to make sure it was intact and that nothing had been left behind in the uterus. After that, the placenta was discarded together with the umbilical cord.</li> </ul> <p><b><i>Nothing was mentioned about the UCB donation or collection.</i></b></p> <p>Around <b>11:10 Am:</b> the mother was stable and was on the phone talking to her family. I closed the curtain and waited for a few minutes until the mother finished her call. I was curious about her response after she realised that she had her baby. Then, 10 minutes later I started talking to the mother.</p> <p><b>Feeling:</b></p> <p>The Mother:</p> <ul style="list-style-type: none"> <li>• Was calm and focused on pushing the baby during labour. Closing her mouth with both hands, no shouting at all. Honestly, I admired her courage and I think this is something that had to do with culture.</li> <li>• After the delivery she was asking about the baby's gender and when the midwife showed her the baby girl, the mother looked a bit weird.</li> <li>• She bit her lips.</li> <li>• Closed her eyes and teared.</li> <li>• Then she said thanks god</li> </ul> <p>This response leads me to infer why she responded this way. After she finished the calls with her family, I</p>
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started a friendly conversation with the mother as following:

**Researcher:** *hey, greeting.*

**Mother:** *greeting back*

**Researcher:** *my name is ... I am I student and doing my research here about the UCB collection. Congratulations, you had a beautiful baby girl.*

**Mother:** *yeah, thank you, May God bless her.*

**Researcher:** *do you have a name for her yet?*

**Mother:** *no, not yet (worried face)*

**Researcher:** *are you ok? You seem worried.*

**Mother:** *no, I am fine. At least I had I healthy baby... glory to God*

**Researcher:** *that is good news (silent for a while)*

**Mother:** *this is my third daughter (biting her lips again) ... anyway I just want to sleep forgive me I am so tired.*

**Researcher:** *Sure, I understand.*

I had a chat with the midwife as well about the mother 5: response:

**Midwife:** *this is her third daughter, and she was hoping for a baby boy. Trying to please her husband...*

**Researcher:** *how did you know that*

**Midwife:** *it is always about husband dear. I know from my own experience.... We all "Bedouin" and we all understand the culture.*

**Note:**

Mother was not happy regarding the midwifery care, she clearly said "I will make a formal complaint against you. No one has the right to shout at me". I felt curious to know where the UCB nurse was. Especially since she's been in the unit for the past 50 minutes. But I preferred to keep silent in order to avoid any changes in the UCB nurse's behaviour if she feels suspicious.

## Appendix G: An example of assessing extracted mechanisms for reliability (in accordance with CR standards)

The example in Figure 24 below, shows how the mechanism on the lack of supportive supervision and leadership was tested for causality using Wynn and William's (2012) test questions.

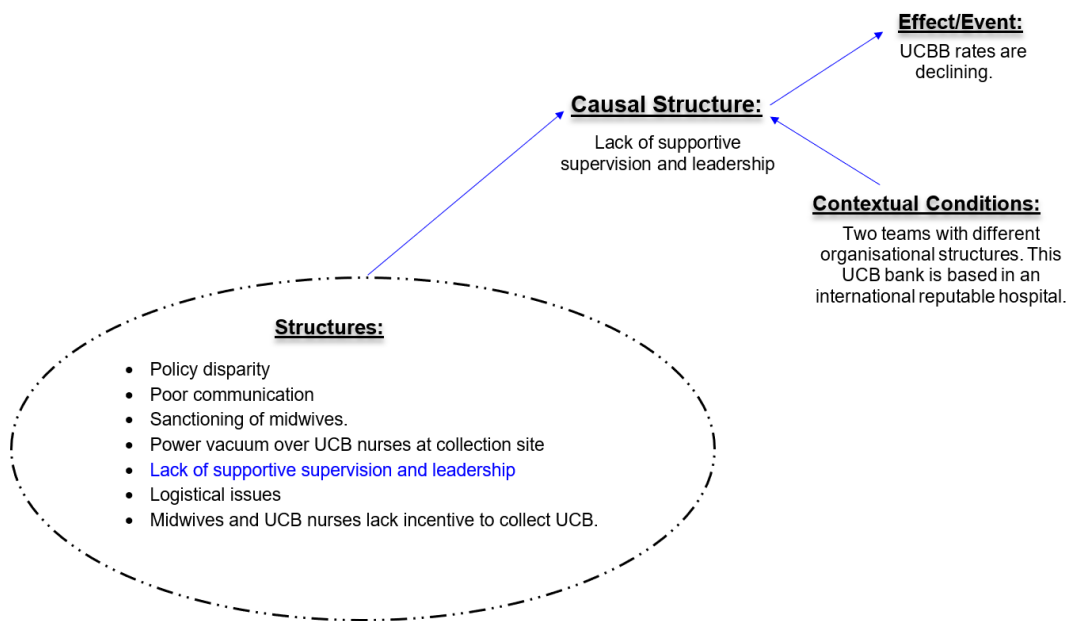


Figure 24. (duplicate) Lack of supportive supervision and leadership mechanism.

Table 23 below shows the short answers for the four test questions for that above mechanism that passed the causal test.



Table 23. Causal test for lack of supportive supervision and leadership mechanism.

Causal Test Question	Answer	Why?
Does the central, causal structure exist in the context of the study?	Yes	<p>The causal structure describes the lack of supportive supervision and leadership that existed, triggering the actions of the PHMD leader to stop her team collecting UCB for the programme. PHMD were made to feel uncomfortable in collecting UCB as seen by the quote below.</p> <p><b>Midwife 3:</b> <i>“I am someone who has been questioned when attempting to collect by [PHMD manager 3] and was told that this is not my job...”</i></p> <p><b>PHMD manager 1:</b> <i>“I will not compromise my human resources for another hospital favour... This is unbelievable! I have not seen any of their [UCB team] supervisors or managers in years! I'm not sure if they're still interested in this anymore. We know nothing about their targets.”.</i></p> <p>In the absence of leadership for the UCB nurses, PHMD leadership felt that they should act as the third-party agent, enforcing acceptable, normative practices on the department. According to the empirical data, the causal structure did exist in the study phenomenon, thus answering the first question in the affirmative.</p>
Are the causal structures affecting the event? Does it have causal power?	Yes	<p>The PHMD manager 3 instructed her department to focus on their roles rather than participate in the UCB programme. This structure cannot be described as causal because there are other structures preceding it, for a structure to have causal power it needs to be the generator rather than a secondary cause of other structures (Wynn and Williams 2012). Through linking structures that could precede the instructions of the PHMD manager, lack of supportive supervision and leadership was the structure that set off a chain reaction of events. The lack of supportive supervision and leadership might be due to a number of reasons, however, proposing structures preceding it would be conjectural in nature. The interviews involved a finite number of participants, none of whom could explain why leadership was not</p>

		clear and why the UCB team did not have supportive supervision. Thus, the lack of supportive supervision and leadership appears to be the causal structure.												
Does the causal structure give reasonable explanations for the phenomena?	Yes	<p>The question here is, does the structure of lack of supportive supervision and leadership for UCB nurses lead to higher or lower UCB rate. As this is qualitative study, causation cannot be quantified, however, we can utilise structures and empirical events to understand UCBC rate changes. Therefore, by doing so, the causal structure of lack of supportive supervision and leadership was retroductively linked to several empirical events. Series of empirical events that point to lack of supportive supervision and leadership mechanism are presented below:</p> <table border="1"> <thead> <tr> <th><b>Empirical Event</b></th> <th><b>Explanation of Event</b></th> <th><b>Relation to causal structure</b></th> </tr> </thead> <tbody> <tr> <td><i>UCB logistical issues</i></td> <td><i>UCB nurses were to register attendance in a different site, shortening their workday and leaving little time to educate mothers and train their PHMD staff.</i></td> <td><i>The logistical issues affecting the UCB team were not noted by management and the time wasted is understood. Managers can disrupt the effectiveness of institutions, such as wasting time on unnecessary commuting.</i></td> </tr> <tr> <td><i>Fear of job loss for foreign PHMD staff</i></td> <td><i>Foreign PHMD staff were afraid of losing their positions if they were to collect UCB. Collecting UCB was against their manager's desires.</i></td> <td><i>This event is a result of the explicit instructions of the PHMD manager who noticed a lack of supervision of the UCB nurses and management of the UCB programme. Midwives were discouraged from engaging with UCBC as the manager did not receive any updates regarding the UCB programme and thus did not see the value of the programme.</i></td> </tr> <tr> <td><i>Incentives and motivation for PHMD</i></td> <td><i>PHMD was under the assumption that they would receive some incentives for collecting UCB units.</i></td> <td><i>Due to the lack of supervision and leadership, staff at PHMD lacked any incentives to collect UCB units. When the lack of incentives was noted, PHMD staff were not able to communicate this to the UCBBH as there was no supervisor on site.</i></td> </tr> </tbody> </table>	<b>Empirical Event</b>	<b>Explanation of Event</b>	<b>Relation to causal structure</b>	<i>UCB logistical issues</i>	<i>UCB nurses were to register attendance in a different site, shortening their workday and leaving little time to educate mothers and train their PHMD staff.</i>	<i>The logistical issues affecting the UCB team were not noted by management and the time wasted is understood. Managers can disrupt the effectiveness of institutions, such as wasting time on unnecessary commuting.</i>	<i>Fear of job loss for foreign PHMD staff</i>	<i>Foreign PHMD staff were afraid of losing their positions if they were to collect UCB. Collecting UCB was against their manager's desires.</i>	<i>This event is a result of the explicit instructions of the PHMD manager who noticed a lack of supervision of the UCB nurses and management of the UCB programme. Midwives were discouraged from engaging with UCBC as the manager did not receive any updates regarding the UCB programme and thus did not see the value of the programme.</i>	<i>Incentives and motivation for PHMD</i>	<i>PHMD was under the assumption that they would receive some incentives for collecting UCB units.</i>	<i>Due to the lack of supervision and leadership, staff at PHMD lacked any incentives to collect UCB units. When the lack of incentives was noted, PHMD staff were not able to communicate this to the UCBBH as there was no supervisor on site.</i>
<b>Empirical Event</b>	<b>Explanation of Event</b>	<b>Relation to causal structure</b>												
<i>UCB logistical issues</i>	<i>UCB nurses were to register attendance in a different site, shortening their workday and leaving little time to educate mothers and train their PHMD staff.</i>	<i>The logistical issues affecting the UCB team were not noted by management and the time wasted is understood. Managers can disrupt the effectiveness of institutions, such as wasting time on unnecessary commuting.</i>												
<i>Fear of job loss for foreign PHMD staff</i>	<i>Foreign PHMD staff were afraid of losing their positions if they were to collect UCB. Collecting UCB was against their manager's desires.</i>	<i>This event is a result of the explicit instructions of the PHMD manager who noticed a lack of supervision of the UCB nurses and management of the UCB programme. Midwives were discouraged from engaging with UCBC as the manager did not receive any updates regarding the UCB programme and thus did not see the value of the programme.</i>												
<i>Incentives and motivation for PHMD</i>	<i>PHMD was under the assumption that they would receive some incentives for collecting UCB units.</i>	<i>Due to the lack of supervision and leadership, staff at PHMD lacked any incentives to collect UCB units. When the lack of incentives was noted, PHMD staff were not able to communicate this to the UCBBH as there was no supervisor on site.</i>												

		<p>The table above gives a few examples of empirical events that could have led to the reduction of UCBC rate. The above empirical events can display how far reaching the lack of on-site supervisor structure is and how many different types of events it generated. This causal structure therefore provides sufficient explanation as to some of the events seen in the demi-regularities.</p>
<p>Do the suggested mechanisms give enough causal depth?</p>	<p>Yes</p>	<p>To test its necessity, CR analysts are advised to look at the events linked to the causal structure and consider if the event would occur should the structure be removed. Thus, we ask the question, if there was a supervisor on site, can we expect to see better interdepartmental collaboration from the heads of PHMD? The answer is most likely, the head of PHMD was mostly concerned with the lack of normative professional values displayed by the UCB department. An on-site supervisor may carry out regulative actions on the UCB department to uphold standards and improve on the teams' work ethic. In addition, other managers of the PHMD spoke to the lack of communication from the UCBBH's administration.</p> <p><i>PHMD manager 1: "How can they expect our support if they are not telling us what to do, and what is going on in this programme? ... Maybe they are satisfied with their current collection rate. How am I supposed to know?"</i></p> <p>This causal structure is necessary as without it, the fall in UCBC rates would not be seen.</p> <p>Lastly, to test the priority of this causal structure other possible causal structures need to be considered. For example, what other structures can lead to the PHMD managers preventing their staff from engaging in UCB unit collection? Professional competition, individual greed, and personal gain are possible structures that can cause this, however, there was no data to suggest the existence of any of these structures. In addition, the simplest answer for the above mechanism and other events is the lack of supervisor on the PHMD wards. This causal structure is therefore necessary and has priority over other structures leading it to be a significant barrier to the UCBC programme.</p>

## Appendix H: Participants' donation consent form for UCBD.

1. Obtain the consent	
(General Organization)	
<p><b>AUTHORIZATION:</b> I have read this information about the donation program or it was read to me. I understand the procedure and I am aware of the benefits and risks. I choose to be in this program. I know I can leave the program at any time and I (and my child) will receive the same medical care. I will receive a copy of this consent form.</p> <p><b>Mother's Name: "Donor"</b></p> <p>_____</p> <p><b>Mother's signature: "Donor"</b></p> <p>_____</p> <p><b>Date:</b></p> <p>_____</p> <p><b>Name of Medical Staff obtaining consent:</b></p> <p>_____</p> <p><b>Signature of Medical Staff obtaining consent:</b></p> <p>_____</p> <p><b>Date:</b></p> <p>_____</p> <p><b>Witness:</b></p> <p>_____</p> <p><b>Date:</b></p> <p>_____</p>	<p><b>إقرار بالموافقة على المشاركة:</b> لقد قرأت بنفسى هذه المعلومات عن برنامج التبرع أو تمت قراءتها لى. إننى أفهم الطريقة وأعرف فوائدنا و مخاطرها. لقد اخترت المشاركة فى هذا البرنامج ، و أنا أعلم أن بإمكانى الانسحاب من البرنامج فى أى وقت و أننى ( وطفلى أيضاً) سألتقى نفس الرعاية الطبية. سأستلم نسخة من نموذج الموافقة هذا.</p> <p><b>اسم الأم المتبرعة:</b></p> <p>_____</p> <p><b>توقيعها:</b></p> <p>_____</p> <p><b>التاريخ:</b></p> <p>_____</p> <p><b>اسم الموظف الذى أخذ الموافقة:</b></p> <p>_____</p> <p><b>توقيعه:</b></p> <p>_____</p> <p><b>التاريخ:</b></p> <p>_____</p> <p><b>الشاهد:</b></p> <p>_____</p> <p><b>التاريخ:</b></p> <p>_____</p>
<p>CONSENT FOR UMBILICAL CORD BLOOD DONATION      ما أفقة عطر التبرع بدم الحبل السرى.</p>	

# Appendix I: Research reflection

## Critical Realism and Agency

I came across CR during my reading for the philosophical underpinning my research. CR was something that profoundly affected my outlook on the use of research for positively impacting people as it highlighted themes such as social justice and equitable access to beneficial structures. Not only did it change my views of using research as a tool for social change, but it also dramatically shifted the way I view the world. I no longer see events happening around me as isolated incidents occurring in space and time, I now begin to see the thread by which events and phenomena interconnect and link with each other, connected by threads of existence.

However, the road to feasibly adopting CR was a long and laborious one, one with many pitfalls and frustration. The language in CR was difficult for me, I had less confidence in my understanding of these abstract concepts due to some language barriers, I felt that although the meta-theory was suitable, I may not be well-suited to using it. To overcome those obstacles, I found videos, podcasts, and research to aid me in grasping the tough, abstract assumptions of the paradigm. I also sought the advice given by other CR researchers, such as Danermark et al. (2002), Sayer (2000) and Wynn and Williams (2012). The adaptation of CR in by these authors greatly aided me in deciphering and using the concepts that seemed so alien and foreign to me at the start of reading.

Agency was an area in CR that I had struggled to understand. Porter (2015) had explained that the agency in CR was seen as separate to structures but were linked and were influential to one another. While I understood this in concept, I found it difficult to see agency as separate to structures in my own data. I had somehow thought that agency was an empirical event caused by certain structures, for example should someone have the resources to, they should be able to spontaneously book a flight to a remote island somewhere. Upon further reading by Williams (2017), I found that my data had many instances where agency and structure were separate entities and could be seen as thus. When the mothers were presented with official fatwas on ideas on mixed lineage and the permissibility of the procedure, they were more likely to participate. In this example, agency was directly linked with the training and education structure. Mothers that were armed with knowledge of the programme were likely to donate quietly, to avoid confrontation with husbands, or discuss with their husbands and donate.

In the future, I think I will continue to follow this method of reading relevant and comparable literature within my field. Although I now have more confidence in my own linguistic capabilities, I think it is important to see how my understanding of concepts fits into the wider research community. Critically reviewing surrounding research and seeing its applicability to my own was beneficial to me and my own thesis. As CR denotes, nothing occurs in a vacuum, research should not either (Mearns 2011).

### **Data Analysis**

Another major obstacle I had to face was the data collection. The UCBBH was a reputable hospital, with seemingly powerful links to the aristocracy. I was anxious about probing into the UCB programme as any critiques of the running of the programme would be inadvertently criticising powerful individuals. This was further exacerbated by the way I felt that some information was being withheld from me.

What had aided me in overcoming this, however, was to use the methods of communication by Yates and Leggett (2016), which helped participants to open up to me. I had initiated interviews with formality, thinking that the participants would appreciate professional conduct. However, Yates and Leggett (2016) explain that using relaxed body language, appearing warmer and human allows for participants, in turn, to be more authentic. Upon reflecting on my own conduct and relaxing my body language and communication, participants seemed to be more comfortable in the interviews and led to more authentic dialogue.