

**EXPLORING PROSTATE CANCER EXPERIENCES  
AMONG JORDANIAN MUSLIM MEN**

**BY**

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## **ABSTRACT**

Over the last decade, prostate cancer has been the most common cancer among men around the world. This study explores the experiences of this illness among a group of Jordanian Muslim men. The study aims to identify the impacts and challenges these men face throughout their experiences with cancer. Through the exploration, the study also focuses on the effects of these impacts and challenges on the men's bodies, lives, and their identity, particularly gender. The study used 'biographical disruption' and 'liminality' theoretical concepts of illness narrative and the works of Connell (2000, 2002, 2005) on gender as a theoretical framework. It adopted a qualitative narrative approach in order to understand this cancer experience among these men. Fifteen Jordanian Muslim men, who had been treated with radiotherapy and hormonal therapy, were recruited, and interviewed to narrate their stories with prostate cancer. Three narrative analytical approaches (thematic, holistic form, and Bamberg's positioning model) were used and integrated with the study's theoretical framework for analysing the men's stories.

Five main key findings resulted from the analysis as follows. First, there is a range of common and specific disruptive impacts and challenges facing these men compared with other men who have similar experiences. Second, there are differing experiences of prostate cancer among these men across the cancer trajectory and over time. Third, the family of the affected men are involved and become a part of this illness experience along with the direct involvement of the healthcare providers with the men. Fourth, there are interactions and influences between the cancer experience and the men's masculinity. Fifth, the complexity of this experience has an influence on the men's identity as Jordanian Muslim men. The study, therefore, adds to the existing knowledge about the experience of prostate cancer by understanding how it can be from (Jordanian) Arabic Middle Eastern and Islamic contexts. The study concludes with implications and recommendations for nursing practice, for education, and for illness narrative and narrative research.

# DEDICATION

*To*

*my family, and my future family*

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# **CHAPTER 1: INTRODUCTION**

## **1.1 Introduction and personal interest**

This thesis explores the experience of prostate cancer, the most common cancer among men around the world, from Arabic, Middle Eastern and Islamic contexts. The story behind choosing this research topic began during my work as a nurse. Through my nursing experience and doing a master's degree on cancer and haematology in nursing, I noticed the complexity of the experience these patients go through and the impact on their lives. The topic of sexuality was not raised much among cancer patients in Middle Eastern countries, where the majority are Muslims, and this was a starting point for me. This led me to undertake a master's thesis exploring the impact of male reproductive cancers on sexuality and masculinity. Through doing my thesis, I found that the experience of prostate cancer has mainly physical and psychosocial impacts on men's lives, which can significantly affect their masculinity and gender identity. From there, I started to reflect on how these impacts could affect Muslim men, like me, and wondered how it would affect their lives. I realised that these influences might be quite different for Muslim men than for other cultural groups, and, as a result, they might need individualised healthcare support. I sought studies that would discuss prostate cancer experience among Muslim men and found only limited research discussing the prostate cancer experience among Muslims. From this point, I decided to do a comprehensive study about the prostate cancer experience among Muslim men, how it would affect their lives, and how these men would manage their illness experience.

Studying the experiences of Jordanian Muslim men with prostate cancer, as a sample, may help in capturing and understanding this illness experience from wider Islamic and Middle Eastern contexts. I start this introduction with some background information about prostate cancer and its situation in Jordan. I then discuss further, the rationale for doing this research, and why exploring this cancer experience among Jordanian Muslim men is important. After that, the research questions and the objectives of this study will be presented and finally, the structure of the thesis with a chapter-by-chapter summary of its content will be outlined.

## **1.2 Background**

### **1.2.1 Prostate cancer overview**

The prostate gland is an exocrine gland and part of the male reproductive system, its main functions are to control the flow of urine and to produce the fluid that protects and nourishes

sperm (Peate & Nair, 2015). Over the last decade, the cancer of this gland has been the most common cancer among men around the world (Fitzmaurice et al., 2018; Global Burden of Disease Cancer Collaboration, 2015). A recent study shows around 1.3 million men were diagnosed with prostate cancer in 2018, in more than 106 countries, but mostly in Central and South America, Western and Northern Europe, and sub-Saharan Africa (Culp, Soerjomataram, Efstathiou, Bray, & Jemal, 2020). Large numbers of men with prostate cancer attract the attention of researchers, particularly in the Western world, who are interested in learning about this disease and men's illness experiences.

Studies of the prostate cancer experience show that men suffer from physical and psychosocial effects throughout their illness. They face a range of challenges beginning with physical and psychological distresses from pre-diagnosis symptoms, such as difficulty and pain with passing urine (Appleton et al., 2015; Tikkinen et al., 2018), or from anxiety, depression, pain, and bleeding, which are associated with investigative tests for prostate cancer (Heyes, Harrington, & Paterson, 2011; Ilic, O'Connor, Green, & Wilt, 2011; Schildmeijer, Frykholm, Kneck, & Ekstedt, 2019). At the time of the diagnosis, men may feel anxiety, uncertainty about their lives, a fear of death, and they are likely to make themselves socially isolated (Appleton et al., 2015; Chambers et al., 2018; Ettridge et al., 2018). Even when they go through their cancer treatments, most experience sexual dysfunction and urinary problems as common side effects of prostate cancer treatments (Blomberg et al., 2016; Rivas et al., 2016). These side effects can persist for as much as 18 years post-treatment (Gegechkori, Haines, & Lin, 2017; Lehto, Tenhola, Taari, & Aromaa, 2017).

The impact of this cancer experience can affect men's identity. Kelly and Millward (2004) explain that the illness experience can affect identity, as both identity and illness interact with biological, physical, psychological, and social dimensions of the affected person. It is worthwhile to consider how prostate cancer in particular impacts the physical, psychological, and social aspects of a man's life and can by extension influence his identity. Studies like those of Cayless, Forbat, Illingworth, Hubbard, and Kearney (2010), and Hubbard and Forbat (2012) show that the prostate cancer experience can alter a man's internal sense of self and self-image. Other studies, such as those by Chapple and Ziebland (2002), Gannon, Guerro-Blanco, Patel, and Abel (2010), Grunfeld, Drudge-Coates, Rixon, Eaton, and Cooper (2013), Maliski, Rivera, Connor, Lopez, and Litwin (2008), and Oliffe (2006) focus more on the impacts of this cancer experience on the gender aspect of men's identity. These studies indicate that the prostate cancer experience mainly affects men's identity by its influences on their physical strength,

expressing emotions, and ability to maintain their social roles. Some studies add that the same cancer experience can challenge gender identity by threatening masculine signifiers. For example, the negative emotions like pain, uncertainty, and fear of cancer or death conflict with the masculine ideal of stoicism for some men (Ettridge et al., 2018; Oliffe, 2004). Similarly, erectile dysfunction resulting from prostate cancer treatment may act as a major threat to the masculinity of many, because of the importance of potency as a symbol of masculinity (Chambers et al., 2018; King-Okoye, Arber, & Faithfull, 2017; Rivas et al., 2016).

This cancer experience may be very different for Muslim men than for non-Muslims. For example, Taghipour (2009) in his thesis on Iranian Muslim men with prostate cancer, noted how urinary problems interfere with maintaining Islamic rituals, such as performing the five obligatory prayers, attendance at the mosque, or pilgrimage. Hence, the impact of the prostate cancer experience may have an influence on religious aspects of the Muslim man's life. In addition, Taghipour (2009) and Iyigun, Ayhan, and Tastan (2011) pointed out that Muslim men with prostate cancer found it difficult to discuss their urinary and sexual problems in front of a female health provider.

The fact that 24% of the world population are Muslims, that equals to 1.8 billion people, with the majority of them living in the Asia-Pacific region, makes studying the prostate cancer experience among Muslim men an important priority (Lipka & Hackett, 2017). Jordan, as a part of this region, has a high prevalence of prostate cancer compared with other countries in the same region. This makes Jordan a particularly suitable place to explore and study prostate cancer experiences among Muslim men.

### **1.2.2 Prostate cancer in Jordan**

Jordan, or the Hashemite Kingdom of Jordan, is an Arab country located in Western Asia with borders to Syria, Iraq, Saudi Arabia, and Israel (One World Nations Online, 2020). The geographical location and the history of Jordan result in people speaking the Arabic language, adopting Arabic culture, and following the Islamic religion (Shoup, 2007). With a population of around 10 million people, 93% of Jordanians identify themselves as Muslims (Bell, 2012; One World Nations Online, 2020). Therefore, Jordan is considered a part of the Arabic, Middle Eastern and Islamic worlds.

Cancer is the second leading cause of death among Jordanians after cardiovascular diseases, according to recent statistics (Ministry of Health, 2016). The prostate cancer mortality rate in Jordan is 5.3%, which places this cancer in third place after breast and colorectum cancers

(World Health Organization, 2020). The incidence rate is also high compared with other countries in the Western Asia region (Roshandel, Boreiri, Sadjadi, & Malekzadeh, 2014). Over the past ten years, prostate cancer has been one of the top five cancers among Jordanian men (Abdel-Razeq, Attiga, & Mansour, 2015; Ismail, Soubani, Nimri, & Al-Zeer, 2013). In 2020, there were around 451 new diagnoses of Jordanian men with prostate cancer in comparison to 218 in 2010 (Abdel-Razeq et al., 2015; World Health Organization, 2020). This indicates that the number of prostate cancer cases is growing.

Prostate cancer in Jordan has received limited attention with regard to cancer research, prevention, and care, where most attention according to Abdel-Razeq et al. (2015) and Abuadas, Petro-Nustas, Albikawi, and Nabolsi (2016) has focused on breast and lung cancers, given they are two of the most common cancers among Jordanians. Prostate cancer diagnostic tests in Jordan can be performed in both private and governmental health sectors for patients who are over 40 years of age and have lower urinary tract symptoms (Abuadas et al., 2016). There are some studies on prostate cancer among Jordanians such as Al Qadire, Alkhalaileh, and Al Bashtawy (2019), A. M. Saleh, Ebrahim, Aldossary, and Almutairi (2020), and A. M. Saleh, W. Petro-Nustas, et al. (2020) that focus on identifying prostate cancer risk factors, screening benefits and barriers, and even on evaluating educational programmes on screening or adopting a healthy lifestyle. In terms of cancer care, Abdel-Razeq et al. (2015) point out that comprehensive and multidisciplinary cancer care in Jordan is still not well developed, even though the cancer care provided is reasonably advanced compared with other neighbouring countries. They also indicate that there is only one specialised Jordanian cancer centre (King Hussein Cancer Centre) which is connected to other international cancer centres and provides psychosocial services to cancer patients in addition to their cancer medical treatments.

I believe that there will be some benefits to be gained from exploring and understanding the prostate cancer experiences among a sample of Jordanian (Muslim) men. The anticipated benefits are primarily to help identify the special needs for this group of men, which in turn can help nurses to provide the cancer care that will promote the men's quality of life. This study aims to identify themes and potential research topics which will benefit other Middle Eastern men who share cultural values and Islamic beliefs prevalent in Jordan. In addition, these themes may be useful for nursing and medical practices in non-Muslim countries when they care for Muslim men with prostate cancer, who have some similarities with the men in this study sample, to meet their unique health needs and ensure cultural safety.

### **1.3 Rationale for the study**

The rationale for this research is evident from the benefits outlined above. The rationale is also developed from two important knowledge gaps. The first is that, to the best of my knowledge, there have been no in-depth studies, which have explored the prostate cancer experience from an Islamic context. A few studies, such as the studies of Iyigun et al. (2011) and Taghipour (2009) have highlighted some of the impacts of the prostate cancer experience and its religious challenges on Muslim men, but these studies focus only on part of the prostate cancer experience and not on its entirety from start to finish.

The second knowledge gap is in the impact of prostate cancer on identity, specifically on gender (masculinity) of Jordanian Muslim men with prostate cancer. Masculinity is constructed by social, historical, and cultural contexts and is shaped by many factors such as geography, ethnicity, and religion (Beynon, 2002). This suggests that both masculinity and other factors are likely to differ from context to context and from religion to religion. Therefore, the impact of the prostate cancer experience on the forms of the masculinity of Jordanian Muslim men may differ from its impact in the Western world.

### **1.4 Research questions and objectives**

The main aim of this research project is to explore the experience of prostate cancer from pre-diagnosis through therapy as described by a group of Jordanian Muslim men. To achieve this aim, I developed three research questions and three objectives:

#### **1.4.1 Research questions**

1. What are the impacts and challenges faced by Jordanian Muslim men during their experiences with prostate cancer, as revealed by their stories about this illness?
2. How do their stories explain their responses to these impacts and challenges?
3. How do their experiences with prostate cancer affect their identity, especially in relation to gender?

#### **1.4.2 Research objectives**

1. To explore the impacts and challenges facing Jordanian Muslim men during their cancer experience on social, and religious aspects of their lives.
2. To explore their responses, and adaptation to these impacts and challenges.<sup>1</sup>

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<sup>1</sup> Adaptation according to Bury (1991) means how to manage chronic illness through coping and using strategies.

3. To examine the impacts of this experience and its challenges on their identity, and gender identity in particular.

## **1.5 The structure of the thesis**

This thesis consists of seven chapters, including this introduction. This chapter presents my personal interest in choosing the research topic, the background and rationale for the study, and finally the research questions and objectives.

Chapter 2 is the literature review and framework chapter. It has four sections. The first section outlines the type of literature review in this thesis and search strategy. The second section presents an international literature review of the experience of prostate cancer. The review focuses on the main impacts and challenges men face during their entire cancer experience. Then, I raise a few important points about the prostate cancer experience, to capture this cancer experience from a Jordanian Islamic context. The third section discusses gender (masculinity) through Connell's works on gender relations and how it fits in with understanding possible configurations of masculinity in Jordanian Muslim men. In this section, I present the literature on prostate cancer experiences and masculinity, and then I integrate how the experience possibly affects the masculinity and gender identity of Jordanian Muslim men. In the last section, I demonstrate theoretical concepts used in illness narrative (illness stories), to establish a theoretical framework that helps in understanding the experience of prostate cancer among the participants of the study.

Chapter 3 is the methodology chapter. It has two main sections. The first section discusses how the research design and methodology of this study were developed in five steps. The section begins with a discussion about how the philosophical approach underpins this study. It then continues with the rationale for choosing a narrative research approach, and how the data can be collected. In the last step, the section explains three narrative analytical approaches, integrated with the theoretical framework of the study discussed in Chapter 2. The second section of the chapter shows how the research process operated. It describes the steps of choosing the setting of the research, obtaining ethical approval, sampling, interviewing the participants, the analysis process, and finally how I maintained research trustworthiness during the research process.

Findings from the study are presented in three chapters; Chapters 4, 5, and 6. Chapter 4 provides an overview of prostate cancer experiences among the participants of this study. It demonstrates that the prostate cancer experience is filled with challenges and disruptive

impacts, which can affect the men and the physical, psychological, social, and religious aspects of their lives. At the same time, it discusses the varied experiences of these challenges, disruptive impacts, and the men's responses to these challenges and disruptive impacts. It finally outlines the influences of cancer perception, Islamic faith, the support, and involvement of healthcare providers and families on the men's responses to their illness.

Chapter 5 gives a picture of the prostate cancer experience of the men in this study. Through five themes, this chapter demonstrates more details about their cancer experiences after the diagnosis and through their treatment periods. Each theme shows a part of the men's cancer experiences, such as their experiences with radiotherapy, sexual dysfunction, and other treatment complications. Within each theme, the chapter presents the disruptive impacts and challenges facing these men in each part of the illness experience, and how it affected their bodies, their lives, and hence their sense of themselves. The chapter also highlights the men's responses and their attempts to face these impacts and challenges. Finally, the chapter stresses the influence of family involvement on this illness experience.

Chapter 6 discusses the interactions between the men's masculinity and the prostate cancer experience. It shows the impacts of this illness experience on different aspects of some of the men's hegemonic, Arabic and Islamic sense of masculinity, which in turn can affect their gender identity. But at the same time, it demonstrates how most of the participants express their masculinity during the experience with this illness. At this point, the chapter highlights the influence of these men's masculinity on their health behaviours, and responses to their illness.

The final chapter, Chapter 7, firstly presents a summary of the study's research questions, its theoretical framework, and the key findings of Chapters 4, 5, and 6. Secondly, the chapter presents the discussion that comes from the key findings of this study to reflect the prostate cancer experiences among the participants and compares them with the experiences of other men. After the discussion, the chapter shows the main strengths and limitations of this study in terms of the nature of the study, its theoretical framework, its sample, and its findings. Lastly, the chapter points out the implications and recommendations of the study in relation to healthcare practice, education, and theory.

# **CHAPTER 2: REVIEW OF LITERATURE AND THEORETICAL FRAMEWORK**

## **2.1 Introduction**

This chapter presents in two interrelated parts; a literature review on the prostate cancer experience of men in general, and theoretical framing to study and understand these experiences among Jordanian Muslim men.

The chapter has four sections. Section one outlines the type of literature review in this thesis and how it was conducted and revisited. Section two presents an overview of the literature on prostate cancer experience/s in terms of the main impacts and challenges men face during their cancer experiences, and how they in turn respond to them. Due to the limited research focused on Jordanian Muslim men with prostate cancer, I initially discuss this from the general perspective of these impacts and challenges on men, and the responses throughout their cancer experiences. Then, I discuss what has previously been published about this cancer experience from the perspective of Jordanian Muslim men.

Section three builds on this literature; it discusses masculinity in relation to the prostate cancer experience. Here, I briefly discuss identity and gender identity then continue the discussion with Connell's works on gender relations, as the focus of this study is on gender. I use Connell's model of gender relations as a framework to discuss possible configurations, or forms of masculinity, in Jordanian Islamic society, which has included both Arabic and Islamic influences. Then, I present the literature on how prostate cancer experience has affected the masculinities of men from different backgrounds. At the same time determining how understanding this experience may help understand issues of masculinity in Jordanian Muslim men with prostate cancer.

Finally, section four reviews how the illness narrative can help in studying and understanding illness experiences, including the prostate cancer experience. I present two useful theoretical concepts— biographical disruption and liminality— that have been used and adopted in narrative studies that examine the experiences of men with prostate cancer. Through this discussion, I develop the significance of adopting these two concepts as a framework for this study, to get a better understanding of prostate cancer experiences among Jordanian Muslim men.

## **2.2 Section one: the type of literature review**

### **2.2.1 Narrative literature review and search strategy**

The type of literature review for this research is a narrative literature review. Unlike other types of reviews such as systematic review, the narrative literature review has no specific method or protocol for searching, no inclusion or exclusion criteria, and it is not necessary to critically review of relevant studies of a topic-related research area (Enferm, 2007; Pae, 2015). Although the findings from this type of literature review may not present evidence in the same way as a systematic review, it still gives a broad overview of a research topic area, addresses the knowledge base, and leads to the identification of research gaps (Pae, 2015).

Searching of the literature was ongoing until the submission of the thesis for examination. Searching was carried out in five databases, Ovid, CINAHL, Web of Science, PubMed, and Google Scholar. Since the focus of this research is on Muslim men with prostate cancer, the initial search words used were “prostate cancer” and “Muslim”. I often replaced the search word “Muslim” with “Arab” or “Middle East” since Arabic Middle Eastern regions mostly have Muslims. Additional search words were introduced such as “experience”, “narrative”, “identity”, “gender”, or “masculinity” to enhance the searching. The search used various combinations using the terms “AND” or “OR”.

Very few results eventuated from searching on the experiences of Muslim men with prostate cancer and its impacts on their lives and gender identity. Thus, I expanded the search strategy by removing the word Muslim and focusing on the search words prostate cancer, experience, narrative, identity, gender, and masculinity separately and then in different combinations. I managed to get a broad overview of prostate cancer experience/s among men from different backgrounds and throughout their cancer trajectory. Using these search terms also introduced me to the theoretical concepts “biographical disruption”, “liminality”, and some of Connell’s works on gender. This was the beginning of developing the theoretical framework of this research. Additional searching was conducted on biographical disruption, liminality, and Connell’s works on gender.

The search terms and criteria changed slightly after the decision was made to recruit Jordanian Muslim men with prostate cancer which had necessitated radiotherapy with hormonal therapy. The word “Jordanian” was added to the previous search terms to get more specific literature in terms of prostate cancer experience or gender identity (masculinity). The focus of searching became more on prostate cancer studies with participants who had radiotherapy or hormonal

therapy. Any type of article that discussed prostate cancer among men who had radiotherapy and hormonal therapy was accepted. The literature was updated while doing the final draft of this thesis for examination.

## **2.3 Section two: impacts and challenges of prostate cancer**

### **2.3.1 Prostate cancer experience/s: an overview**

The literature on the prostate cancer experience shows that men face a variety of challenges and impacts which affect their bodies and their lives. These challenges and impacts begin before the cancer diagnosis. In the pre-diagnosis period, men with prostate cancer may experience urological symptoms such as urine urgency, nocturia, difficulty passing urine or changes in sexual functions, such as erectile dysfunction, and inability to reach orgasm (Devlin, Whitford, Denson, & Potter, 2019; Tikkinen et al., 2018). These symptoms may cause physical discomfort, tiredness, and psychological distress, as well as their sexual life being affected (Appleton et al., 2015; Ervik & Asplund, 2012).

The literature shows that prostatic cancer diagnostic tests have impacts on men and may be a significant trial. Men usually go through three possible diagnostic tests to confirm their prostate cancer diagnosis: digital rectal examination (DRE), prostate-specific antigen (PSA) blood testing, and transrectal ultrasound-guided prostate biopsy (TRUS-bx). Several studies outline different physical and psychological impacts from these tests, which also become part of the pre-diagnosis challenges. For example, men from different cultural backgrounds claim discomfort, pain, embarrassment, and humiliation from their experience with DRE (Appleton et al., 2015; Furlan et al., 2008; Ramalho Romero et al., 2008; Winterich et al., 2009). In the case of the PSA blood test, varied studies note that men commonly do not know much about this test or why it is used (Appleton et al., 2015; Ervik & Asplund, 2012; Heyes et al., 2011). These studies also report receiving limited information from health professionals about the test, which makes it a challenge for men to understand their condition. Another challenge comes from their experience of anxiety while waiting for the results (Schildmeijer et al., 2019).

Apart from the challenges of DRE and PSA tests, the literature shows that many men see the prostate biopsy procedure (TRUS-bx) as the most unpleasant experience of prostate cancer diagnostic tests. During and following the procedure, they may experience physical discomfort, pain, infection, and even bleeding that may last for 4 weeks after the procedure (Appleton et al., 2015; Drummond et al., 2014; Heyes et al., 2011; Tikkinen et al., 2018; Wade et al., 2015). They can also suffer from psychological complications such as stress, anxiety, and fear. These

feelings are not only from the procedure but also from waiting for the results (Heyes et al., 2011; Medd, Stockler, Collins, & Lalak, 2005; Wade et al., 2015). Heyes et al. (2011) found that the procedure causes embarrassment to some men from anal penetration, or from exposing their genital area to health professionals. All of these physical and psychosocial impacts of the biopsy procedure can interfere with many of the symbols of their masculinity including stoicism (Heyes et al., 2011; Oliffe, 2004). This indicates that the experience of the biopsy procedure may challenge masculinity, as discussed in section three of this chapter.

Men continue experiencing difficulties after confirmation of the cancer diagnosis. The literature has shown that men suffer from various emotional and psychosocial impacts from the moment of diagnosis. Overall, most men from a wide range of different ethnicities and backgrounds experience feelings of shock, anxiety, anger, and vulnerability when they learn of their prostate cancer (Appleton et al., 2015; Ettridge et al., 2018; Van Ee et al., 2018). Hagen, Grant-Kalischuk, and Sanders (2007), King-Okoye et al. (2017), Chambers et al. (2018), and Sharpley, Bitsika, and Christie (2018) add that men also experience feelings of frustration, depression, fear of death, and uncertainty about their future life, during and even after the diagnosis period.

The literature has also shown that some men react positively, and cope with their diagnosis of cancer. A meta-synthesis by Rivas et al. (2016) found that some men from religious backgrounds such as Christianity and Buddhism see their diagnosis of prostate cancer as a test of faith; the concept of this test gives them inner strength, and helps them to cope with their illness. Even after the diagnosis, researchers have found that spiritual belief has been significant in helping men face their illness and treatment difficulties. For example, spiritual belief was a key factor in encouraging men to engage with social networking and religious activities, where they feel supported by God, family, friends, and community (Evans et al., 2005; Lephherd, 2013; Rivas et al., 2016; Walton & Sullivan, 2004).

The literature also shows that men with prostate cancer experience a range of challenges and complications linked to various cancer treatments. One of these treatment forms is external beam radiotherapy. In this therapy, men are exposed to high-energy X-ray beams aimed at the prostate from outside the body lasting 15 minutes per day, 5 days per week, for approximately 8 weeks (Zaorsky et al., 2013). Men are required to have a full bladder during each session to reduce radiation toxicity on normal tissue. They may then need to wait up to 60 minutes after drinking to reach the required bladder volume (Holden, Stanford, D'Alimonte, Kiss, & Loblaw,

2014; O'Doherty et al., 2006). A few studies, such as research by Appleton et al. (2015), Holden et al. (2014), and O'Doherty et al. (2006) examine the impact on men of this radiotherapy procedure. They highlight that the radiotherapy procedure causes men some physical discomfort and psychological distress, due to their inability to maintain a constant bladder volume, and because of urgency, and even urge incontinence. There can also be social impacts of this procedure, since coming daily to the radiation session for several weeks may significantly interfere with a man's daily routine activities (Appleton et al., 2015).

In addition, there are many physical and psychosocial consequences from the complications of this radiotherapy treatment. For instance, various studies have shown that this treatment causes urinary and bowel symptoms including pain, discomfort, incontinence, and blood in the urine or from the bowels (Blomberg et al., 2016; Devlin et al., 2019; Van Ee et al., 2018). It can also produce fatigue and alter men's sexual functions, such as reduced sexual desire, erectile dysfunction, and problems with ejaculation and orgasm (Devlin et al., 2019; Maharaj & Kazanjian, 2021; Rivas et al., 2016). The impact of radiotherapy, especially from fatigue and incontinence, can disturb men's work and social life and limit social activities (Paterson, Robertson, Smith, & Nabi, 2015).

These impacts from cancer treatment on men's bodies and on their physical and psychosocial aspects of their life, may also affect their sense of 'being a man'. Alexis and Worsley (2018), Chambers, Chung, Wittert, and Hyde (2017), and Rivas et al. (2016) show that experiencing erectile dysfunction, incontinence, and other physical changes from the prostate cancer treatment, have a negative influence on the masculinity of men in a range of socio-cultural groups, such as hetero/homosexual American, European, Australian, African, Latino, and Asian men. This negative influence is mainly because of the interference of these side effects on men's personal and cultural ideals of what it means to be a man. I discuss the issue of masculinity in greater depth in section three of this chapter.

Another form of prostate cancer treatment consists of hormonal therapy. Men with prostate cancer may have hormonal therapy by itself or with radiotherapy (Mottet et al., 2017). Men receiving hormonal therapy usually suffer from sexual dysfunctions including impotency, loss of libido and sex drive, which creates more psychological distress and tension to their sexual relationships (Chambers et al., 2018; Ervik & Asplund, 2012; Hagen et al., 2007). They may also experience fatigue, decreased muscle strength, and weight gain that makes maintaining their daily and social activities difficult (Ervik & Asplund, 2012). Physical changes such as

genital shrinkage, breast growth, hot flushes, and hair loss may also be experienced (Wibowo et al., 2018).

The literature mentions that men attempt various strategies to cope in response to the common side effects of hormonal therapy. In terms of sexual dysfunction, some men accept it as a normal process of aging, while others use sex aids such as Sildenafil (Viagra) tablets and vacuum erection devices to maintain their sexual function (Dyer, Kirby, White, & Cooper, 2019; Rivas et al., 2016; Van Ee et al., 2018). Hsiao, Moore, Insel, and Merkle (2014) mention a diversity of strategies used by men to manage their urinary and bowel problems. In the case of incontinence (urine and bowel), some men wear pads, or do Kegel exercises to strengthen the urethral sphincter and pelvic floor muscles. Other men limit their social activities or take short trips, to reduce having incontinence incidences outside the home. Lastly, Wibowo et al. (2018) point out various strategies used by men to control some of the hormonal side effects. For example, men wear layered clothing and do deep breathing exercises for hot flushes. They also do exercises to strengthen their muscles, and to reduce the effects of fatigue and weight gain.

Literature indicates that men may endure many difficulties after completion of their cancer treatment. These difficulties can emerge from the concern about cancer recurrence. In this case, men experience distress about the return of cancer or its spreading to other body parts, which makes them experience fear, anxiety, and uncertainty about their future (Eisenberg et al., 2015; Lisy, Langdon, Piper, & Jefford, 2019; Paterson et al., 2015; Rivas et al., 2016; Watson et al., 2016). Other difficulties mainly come from long-term side effects of the treatment. Different studies highlight the negative impact on men's quality of life from the side effects of long-term treatment. After radiotherapy treatment, men may experience a slight recovery of their sexual, urinary, and bowel functions (Donovan et al., 2016; Fischer, 2018). Yet, their sexual, urinary, and bowel problems can also persist for a long time, sometimes up to 18 years after treatment (Gavin et al., 2015; Gegechkori et al., 2017; Lehto et al., 2017). The presence of these problems over a long time builds up more unpleasant feelings such as anxiety and frustration, or disturbs their daily and social activities (Albaugh, Sufrin, Lapin, Petkewicz, & Tenfelde, 2017; Bamidele et al., 2018; McConkey, 2016).

The side effects of long-term treatment can also affect men's ability to work, and many must stop working or take early retirement (Bennett et al., 2018). This may affect their income and cause them financial hardship that negatively influences their quality of life (McLennan,

Ludvik, Chambers, & Frydenberg, 2019; Rivas et al., 2016). Furthermore, the inability to work or financial hardship due to the cancer experience creates another psychological challenge to some men, as they become concerned about the financial consequence on their family (Alexis & Worsley, 2018; Chambers et al., 2018; Grunfeld et al., 2013). This concern mainly links with their personal and cultural role of being a provider of the family, which may influence aspects of their sense of masculinity, as I describe in section three of this chapter.

Generally speaking, men from different backgrounds face a range of negative impacts and challenges throughout their experiences with prostate cancer. As I have noted, the challenges and impacts mostly derive from the physical and psychosocial consequences of prostate cancer diagnostic tests, the diagnosis, the treatment and its acute or long-term side effects. The negative impacts and challenges do affect men's bodies and the physical, psychological, and social aspects of their lives. At the same time, the literature mentions how men deal with these negative impacts and difficulties of their cancer experience by using a mixture of general and distinct coping strategies. It may be concluded that Jordanian Muslim men with prostate cancer would go through the same pathway of this illness experience and would face similar impacts and challenges. Therefore, it is important to discuss the literature that relates to the implications of this cancer experience for Jordanian Muslim men to highlight similarities and differences.

### **2.3.2 The prostate cancer experience/s implications for Jordanian Muslim men**

There are limited studies that discuss prostate cancer experiences among Muslims. Nevertheless, to at least set the general context when considering the responses of Jordanian Muslim men, I present a few important points about Islamic beliefs and Arabic Middle Eastern culture as a starting point to reflect upon how the prostate cancer experience and its challenges could be for them.

The first point is related to the perception of illness, which can have an impact on men's responses to their diagnosis or the illness experience in general. In Jordan, similar to other Middle Eastern countries, having cancer is perceived as hopeless and leads to death (Daher, 2012; Dardas & Ahmad, 2015). This perception is possibly based on people's belief that cancer cannot be prevented and that it is always fatal (Daher, 2012). Another perception of cancer is also linked with stigma. Dardas and Ahmad (2015) found that some Jordanian men consider the diagnosis of a man with cancer as stigma. From these men's perspective, having cancer causes the man to transition from his cultural role as the caregiver of the family to the role of a care recipient. This transition interferes with male Arab culture and may lead to a decline in or

a devaluation of their social status. Therefore, the diagnosis of prostate cancer among Jordanian Muslim men can be stigma for some, which may affect their responses.

Despite these difficulties in an Islamic perspective illness can be viewed variably as a taken-for-granted hardship of life, a test for the believer, destiny, or a way for the expiation of sins (Barton-Burke, Barreto, & Archibald, 2008; Daher, 2012; Rahman, 2015). Several studies show that some Islamic beliefs help Muslim cancer patients and survivors to accept their illness and cope with their cancer experience. Abu-El-Noor and Radwan (2015), Alaloul, Schreiber, Al Nusairat, and Andrykowski (2016), Assaf, Holroyd, and Lopez (2017), and Silbermann and Hassan (2011) indicate that faith in God (Allah) who has the power to cure and protect, and faith in destiny and death, and submission to the will of Allah, have helped Muslims to accept and manage the distress and uncertainties of their diagnosis and experience with cancer. These beliefs give people inner peace, patience, and hope, that offer strength when facing the difficulties through their cancer experiences. Moreover, an assortment of Islamic rituals and religious activities, such as performing prayers, reading Quran (the holy book), or fasting are used as strategies to overcome the impacts and difficulties from cancer experiences (Abu-El-Noor & Radwan, 2015; Alaloul et al., 2016; Assaf et al., 2017). However, some complications from the prostate cancer experience can interfere with the ability of religious men to maintain some basics of Islamic rituals.

There may, however, be negative impacts and challenges of the prostate cancer experience on the religious aspect of life among (Jordanian) Muslim men. Urinary incontinence is one example. Religious Muslims pray five times a day and they need to have a ritual purity to be able to perform the prayers. Two Quranic verses give hints on how to obtain this purity – verse 5:6 “... when you perform prayer, wash your faces and your forearms to the elbows and wipe over your heads and wash your feet to the ankles...”<sup>2</sup> and verse 74:4 “And your clothing purify”<sup>2</sup>. First, a person’s body and his/her clothes should be clean from ‘*Najasah*’ (ritual impurity), and this includes waste products such as urine and faeces. Then, a person needs to do what is called ‘ablutions’, which is a certain way of washing their hands, face, arms and feet. Hence, a Muslim man with urinary incontinence or dribbling, who has a commitment to this form of prayer, might have difficulty maintaining this purity required for performing the five obligatory prayers. Moreover, Taghipour (2009) adds that these symptoms can also affect the attendance of Muslims to mosque or *Hajj* (pilgrimage- another basic Islamic ritual). Urinary

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<sup>2</sup> Saheeh International. (2012). *The Qur'an: English meanings and notes* Jeddah, Kingdom of Saudi Arabia Al-Muntada Al-Islami Trust.

problems could, therefore, add religious challenges to practising Muslim men. Islamic leaders (Imams) can however, provide *Fatwa* (an Islamic advisory opinion) of how men experiencing such challenges might maintain religious rituals with their urinary problems (Miah et al., 2019).

Fasting during the month of *Ramadan*, another basic of Islamic rituals, can be disrupted by an experience such as cancer. Quranic verses 2:183-187 explain about fasting: "... the month of Ramadan is that in which was revealed the Qur'an... So, whoever sights the month, let him fast it; and whoever is ill or on a journey- then an equal number of other days. Allah intends for you ease and does not intend for you hardship... eat and drink until the white thread of dawn becomes distinct to you from the black thread. Then complete the fast until the night (sunset)"<sup>2</sup>. These Quranic texts require Muslims to fast during Ramadan from sunrise to sunset. Even though sick people are exempt from this fasting, some Muslims who are unwell, are determined to fast because and believe that fasting may fight their cancer cells or that they may get more mercy from Allah because of fasting (Maleki et al., 2018; Tazi, 2008). Others reject the idea of not fasting, or they feel guilty for not fasting. On the other hand, some Muslims do not fast because of this religious exemption, the advice of their oncologist, or due to the impact of the cancer treatment on their bodies (Bragazzi et al., 2016; Maleki et al., 2018; Tas et al., 2014; Tazi, 2008; Zeeneldin & Taha, 2012). In the case of prostate cancer, Muslim men may find it difficult to fast in Ramadan due to their cancer or the adverse outcomes on their bodies from treatment which may have a variety of impacts on different men.

The digital rectal examination (DRE) and the prostatic biopsy procedure may also be an issue for Jordanian Muslim men. In Muslim culture, the private area in a male's body (usually between umbilicus and knees) cannot be exposed to, or touched by, others, which may make these prostate cancer diagnostic tests for some Jordanian Muslims an unacceptable and embarrassing procedure (Abuadas et al., 2016; Arafa, Rabah, & Wahdan, 2012). Consequently, the DRE and prostatic biopsy procedure would be a challenge to those Jordanian Muslim men who have this view.

Another, and perhaps most obvious issue is related to urinary and sexual problems from the prostate cancer experience. As noted earlier, these symptoms are considered for some men as a sensitive topic to disclose, particularly so for Muslim men. For men in Jordan and in other Islamic countries, sexual dysfunction is taboo as a topic, that may not be easily discussed with other people, even with other men (Al Momani, Al Hadid, Al Nawafleh, & Al Nawafleh, 2017;

Taghipour, 2009). Therefore, this issue may create a barrier to Jordanian men when prostatic symptoms occur and may cause delays for men seeking medical help.

Finally, dealing with female healthcare professionals may cause another issue for some Muslim men. Some studies show that Muslim men, including Jordanians, usually prefer to express their health concerns to men, or to deal with male healthcare professionals, especially when it comes to private, sensitive health concerns such as sexual dysfunction (Ahmad & Alasad, 2007; Iyigun et al., 2011; M. Y. Saleh, Al-Amer, Al Ashram, Dawani, & Randall, 2020; Shoqirat & Abu-Qamar, 2015; Taghipour, 2009). Iyigun et al. (2011) and Taghipour (2009) highlight that issue when they observed how Muslim men with prostate cancer feel embarrassed or avoid discussing their urinary and sexual problems with female healthcare providers. This may be the same for Jordanian Muslim men with prostate cancer when they deal with female healthcare providers. Hence, the presence of, or dealing with, a female health professional may make it difficult for these men to reveal their health concerns during their experiences with prostate cancer.

I have indicated so far that Jordanian Muslim men may follow a similar pathway as non-Muslim men with prostate cancer. Throughout the experience with this illness, these Muslim men may face negative impacts and challenges that are similar to non-Muslim men, that affect them and the physical, psychosocial aspects of their lives. They may also use their spirituality (Islamic beliefs) like non-Muslims do, to support themselves in coping and overcoming the difficulties from the cancer experience. However, their experiences with prostate cancer can be specific to them as Muslims compared to non-Muslim men. This is because of the interactions between the prostate cancer experience with their cultural values, and Islamic beliefs and rituals. I have addressed some possible interactions between this illness experience with some basics of Islamic rituals, which may mean Muslim men experience more challenges that affect the religious aspect of their life. I have also explained some sensitive issues from Islamic and Arabic Middle Eastern perspectives that these men may face through the cancer experience. I have indicated that those sensitive issues can also create more challenges to these men compared with their non-Muslim counterparts. This again presents the prostate cancer experience as different for (Jordanian) Muslim men.

I have also briefly mentioned in subsection 2.3.1 that the prostate cancer experience has potential impacts on men's masculinity. Many studies have shown the negative influence of prostate cancer experience on masculinity (gender identity). Thus, it is important to discuss

gender (masculinity) in Jordanian Muslim men in order to understand how their prostate cancer experiences could possibly affect their gender identity. I discuss this in the next section.

## **2.4 Section three: identity and gender, Connell's works on gender, masculinity, and prostate cancer experience**

As noted in Chapter 1 and at the beginning of this chapter, there are limited, if any studies discussing the impact of the prostate cancer experience on the identity of Muslims, particularly in relation to gender. Therefore, I begin with a brief introduction to identity and gender. Then, I continue the discussion about gender through Connell's model of the structure of gender relations to explore some possible configurations or forms of masculinity in Jordanian Islamic society. Later, this helps me in reflecting how the prostate cancer experience can possibly affect these configurations of masculinity among Jordanian Muslim men.

### **2.4.1 Identity and gender**

Identity has been largely examined in psychology and sociology studies and theories. These studies and theories argue that identity has a dual concept: an internal (mental) and a social concept. From a psychological view, identity is a mental concept and is “an internal (cognitive) process by which one defines and integrates various aspects of the self” (Deaux, 2000, p. 222). The aspects of the self may include personal traits, goals, beliefs, values, self-esteem, and self-evaluation (Vignoles, Schwartz, & Luyckx, 2011). So, gender identity from this view is “a multidimensional concept, including personality traits, role behaviours, physical characteristics, and other gendered experiences” (Deaux, 2000, p. 223). Identity as a social concept is constructed through social interactions and language, and is shaped by social contexts and cultural discourses (Burr, 2015; Deaux, 2000). Burr (2015) and Vignoles et al. (2011) argue that a person's identity contains multiple factors such as age, social status, ethnicity, religion, gender, and work.

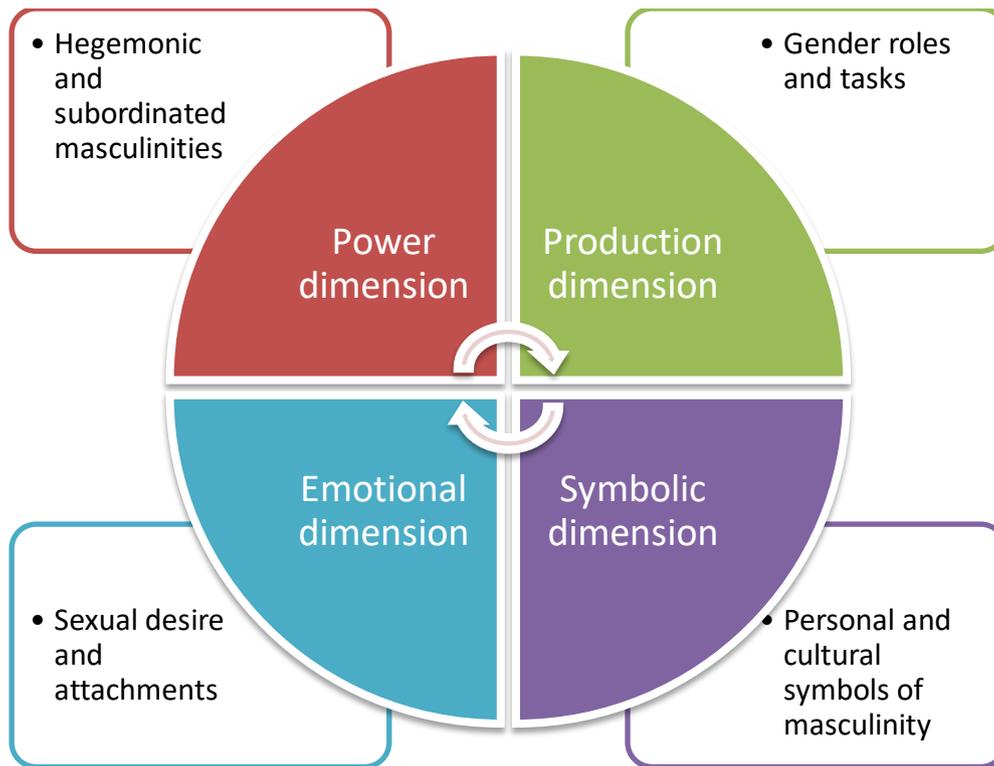
In this research, the focus is more on the gender identity from the social perspective since this perspective considers the Jordanian Arabic and Islamic contexts related to gender. In the case of the participants of this research — Jordanian Muslims— a part of their identity is perhaps shaped by their ethnicity (Jordanian Arab), religion (Muslim), and gender (male) as well as other social discourses such as age and social status. At this point, their gender identity is just an aspect of identity that can be constructed through social interactions and shaped within the discourses related to gender, such as the Jordanian Arabic culture and Islam (the religion).

Thus, the discussion in this section is about gender (masculinity) from the social perspective of identity.

#### **2.4.2 Connell's works on gender**

From the social perspective, and particularly under the social constructionism philosophical approach, gender “is not as a trait of the individual but rather as a process external to the individual, which is defined by interactions between people, by language, and by the discourse of a culture” (DeLamater & Hyde, 1998, p. 16). Connell (2000, p. 24; 2005, p. 71) defines gender as “a structure of social practice” which is generated and organised within social relations among people at intrapersonal, interpersonal, and institutional social levels. The actions, projects, or configurations of this (gender) practice can be called masculinity and femininity (Connell, 2005). But at the same time, Connell (2002) continues addressing the importance of the complex connection of bodies with social practices in people’s daily life. Connell argues that bodies are historically and over time both agents and objects of social practice. For example, Connell explains that female physical capacities to give birth and lactate are linked to the social practice of childcare. The same thing holds true with the capacity of the male body to penetrate and ejaculate, which is linked to the practice of intercourse. At this point, Connell (2005, p. 71) extends the definition of gender to “social practice that constantly refers to bodies and what bodies do, it is not social practice reduced to the body”. Therefore, masculinity can be social practices that symbolically refers to male bodies and what these bodies do.

Connell (2000, 2002, 2005) proposes a model that defines multidimensions of (gender) social relations between people in any society where masculinity is constructed and reproduced. The model consists of four gender relation dimensions: power, production (gender division of labour), cathexis (emotional attachments), and symbolic; Figure 1, is a representation of this model.



**Figure 1:** *A representation of Connell's model of the four dimensions of gender relations*

The first dimension is the power relations dimension. In this dimension, Connell (2000, 2002) explains how power has a significant influence on a society's structure and on the relations among people. Power relations create patriarchal classes and order between people at any social level that make those who have power over others. Gender order in contemporary Western (European/American) societies, as an example, shows that dominance is usually by men with the subordination of women (Connell, 2005). The presence of power and dominance in these societies produces 'hegemonic masculinity'. The concept 'hegemony' is derived from Antonio Gramsci's study of class relations, which refers to a group of people who claim and sustain leadership or dominance positions in social life (Connell, 2005). Thus, Connell (2005, p. 77) defines hegemonic masculinity as "the configuration of gender practice which embodies the currently accepted answer to the problem of the legitimacy of patriarchy, which guarantees (or is taken to guarantee) the dominant position of men and the subordination of women". Connell (2005) also indicates that the power relations and hegemonic practices can also be between men within the same society, which as a result creates different types of masculinities among these men. Later, Connell and Messerschmidt (2005, p. 841) describe hegemonic masculinity as "a range of popular ideologies of what constitute ideal or actual characteristics of 'being a man'". Connell and Messerschmidt seem to suggest here that hegemonic masculinity becomes the most valued masculinity form in a society and its ideologies are the normative standards

which men can aspire. If men do not meet or conflict with these ideologies or standards, they are “expelled from the circle of legitimacy” and their masculinities are subordinated, such as homosexual men (Connell, 2005, p. 77).

The second dimension is the production relations dimension or the gendered division of labour. Connell (2002) argues that the history and culture of any society have an influence on assigning men and women to certain tasks and jobs. At a family level, as an example, men in many societies are designated as providers while women do housework and childcare. Hence, masculinity in these societies is closely connected with being a wage earner where femininity relates to housework and child caring (Connell, 2002). However, Connell (2014) highlights the influence of globalisation, colonisation, economic demands, and modern Western culture on changing the gender division of labour, also affecting the social relations of people in the southern part of the world. Applying this dimension to the real-world, masculinity is not necessarily connected with the traditional male tasks and jobs because men and women nowadays are now both taking part in the labour market.

The third dimension is cathexis emotional relations. Connell (2002) maintains that emotional attachments, desires, and commitments such as social practices are where masculinity is constructed. Connell argues that social practices and relationships between people are mainly charged with emotions. At this point, Connell gives the example of sexuality and its connection with gender. People do have emotional attachments and sexual desire for others as a part of their social practices. Their emotional attachments and sexual desire commonly lead to having heterosexual or homosexual relationships and social practices, which eventually produces the heterosexual and homosexual type of masculinity (Connell, 2002). Moreover, emotional attachments in this dimension are not only present in sexuality but also in emotional commitments. Connell (2002) points out that people may show their commitments to their families or to their nation by sacrifice and fighting to protect them. This means that fighting or sacrifice for family or nation are considered as forms of social practices where masculinity is also constructed and demonstrated.

The fourth dimension is the symbolic relations dimension. In this dimension, Connell (2000, 2002) discusses the tremendous influence of history, culture, and language of a society in categorising gender and the meaning of what is a ‘man’ (masculine) or a ‘woman’ (feminine) in its people. For example, Connell explains that the culture of a society usually has rules or a structure of gender symbolism to consider how an individual or his/her action complies with a

gender category (masculine/feminine). People normally take these rules for granted and apply it on themselves in everyday social practices to express their masculinity or femininity, such as dress style, and body gestures. In the case of masculinity, male biological traits, stoicism, dominance, and independence are examples of signifiers of masculinity in Western culture (Moynihan, 1998).

Finally, Connell (2002, 2005) discusses that there is dynamic interaction within the four dimensions of gender relations and that they are subject to change in terms of forming and transforming over time. For example, Connell (2005, p. 76) indicates that hegemonic masculinity is “not a fixed character type, always and everywhere the same. It is, rather, the masculinity that occupies the hegemonic position in a given pattern of gender relations, a position always contestable”. Here, Connell argues that these dynamic, forming and transforming dimensions of gender relations make gender more fluidly constructed, which supports the view on ‘doing or performing gender’ by Butler (1990), and West and Zimmerman (1987). They assert that masculinities are not only constructed and reproduced by social relations but also performed (differently) through practising those relations.

Apart from the dynamic gender relations dimensions, Connell (2005) highlights that gender as a structure of social practice also interacts with other social structures, such as race and class. This, as a result, creates different versions of masculinities like the masculinities of white men and black men. Masculinities here become more complex and are shaped differently, as intersecting with other sociocultural factors, such as religion, geography, income, level of education and so on (Beynon, 2002). In the case of Jordanian Muslim men, they perhaps have different forms of masculinities that can be shaped by intersecting with their Arabic Middle Eastern culture and religion of Islam.

I have adopted Connell’s works on gender and the model of gender relations for two reasons. Firstly, Connell’s works have been used in studying and understanding masculinities presented in Arabic Middle Eastern and Islamic societies, such as studies of Adibi (2006), Aslam (2012), Inhorn (2012), and Ouzgane (2006). These studies present a range of configurations of masculinity from Arabic, Middle Eastern, and Islamic perspectives. These studies help me later to understand and explore some possible configurations of masculinity in Jordanian Muslim men, who perhaps link the men in these studies with their forms of Arabic Middle Eastern and Islamic masculinities. Secondly, Connell’s works have a big influence in the health context for understanding gender-related practices and behaviours in Western and Middle Eastern cultures,

such as studies of Adibi (2006), Connell (2012), Courtenay (2000), Inhorn (2003), Obeisat, Gharaibeh, Oweis, and Gharaibeh (2012), and Schofield, Connell, Walker, Wood, and Butland (2000). These studies indicate the influence of these different forms of masculinity, especially hegemonic masculinity, on health behaviours, resulting in negative practices such as violence, denying having health problems, or ignoring illness symptoms to show power and strength. Other studies have used Connell's works to examine the impact of prostate cancer experiences on Western aspects of masculinity such as those of Broom (2004), Chapple and Ziebland (2002), and Wall and Kristjanson (2005). These, of course, help me to observe the interactions between masculinity and the prostate cancer experience to consider the impact of the cancer experience on Jordanian Muslim men.

### **2.4.3 Masculinity and Jordanian Muslim men**

As mentioned in Chapter 1, the majority of Jordanians speak the Arabic language, adopt Arabic Middle Eastern culture, and follow Islam, due to the history and geographical location of their country (Shoup, 2007). As a result, Arabic Middle Eastern culture and Islamic regulations have a strong impact on social relations and practices between Jordanian Muslim people where their masculinity can be constructed and presented (Jabiri, 2016). In Connell's works on gender, masculinity in any society is constructed and performed through four gender relation dimensions: power, production, emotional, and symbolic. These four relation dimensions can be reflected in a Jordanian Islamic society in the following ways.

In the power dimension, Jabiri (2016) indicates that the Jordanian society— as in most Middle Eastern societies— adopts the patriarchal structure where men mainly have the authority. Adibi (2006) and Inhorn (2012) stress that this patriarchal framework is a source of Arabic 'hegemonic masculinity' and it gives men the authority to control who is subordinate to them. At the family level as an example, the head of the family is a man, and he has the power to exhibit his hegemonic masculinity over his family. Moreover, the dominant form of Islam amongst Jordanian Muslims is the Sunni Islamic school. This school stresses men's responsibility and accountability to their families in term of guardianship (Jabiri, 2016). Aslam (2012) indicates that these extra responsibilities and religious accountability are based on the Quranic verse 4:34. The verse says: "Men are in charge of women by the right of what Allah has given one over the other and what they spend for maintenance from their wealth ..."<sup>3</sup>. Muslim men may consider their responsibilities as a privilege to have power over their families,

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<sup>3</sup> Saheeh International. (2012). *The Qur'an: English meanings and notes* Jeddah, Kingdom of Saudi Arabia Al-Muntada Al-Islami Trust.

which consequently reinforces a patriarchal family structure and hegemonic masculinity (Inhorn, 2012; Siraj, 2014). In this case, Jordanian Muslim men can present forms of Arabic hegemonic and Islamic masculinities in the power relations dimension through guardianship, being the decision maker and the head of the family.

In the gendered division of labour (the dimension of production relations), men can construct and present their masculinity through their gender roles and work tasks. In Middle Eastern societies, there are Christians, Jews, and other people from different religious backgrounds besides Muslims. Regardless of the religious background, masculinity in these societies is mainly linked with being a wage earner, the provider for the family (Adibi, 2006). In Jordan, Shoup (2007) shows that men are the ones who pay the dowry to their brides, cover wedding expenses, and later bear the financial burdens of their families. Nasser El-Dine (2018) points out that the current economic situation in Jordan puts young Jordanian men in a difficult position to meet the cultural needs of getting married and having a family. Nevertheless, these men still try to exhibit their masculinity through their financial duties before or after marriage, such as providing material gifts for their partner. From this cultural perspective, Jordanian men can demonstrate a form of an Arabic Middle Eastern masculinity through their ability to be the financial provider for their families.

In the production relations dimension, Islam directs men to fulfil certain roles or tasks, especially towards their families. The Quran describes some of these male roles. According to the Quranic verse 4:34, husbands and fathers are responsible and religiously accountable for protecting their wives and children and keeping them well-fed and comfortable (Aslam, 2012; Siraj, 2014). Thus, a Jordanian Muslim man's role can be more than traditional, but a religious task as well. Even with the changes of modernisation and increases in sharing the labour market between men and women, there are Jordanian men who do not support women working outside of the home, as they consider this a defining part of their male identity (Shteivi, 2015).

In the third emotional dimension, a configuration of masculinity among Jordanian Muslim men can be constructed and performed through their attachments (sexuality) and commitments. Sexuality features prominently as a point of religious regulation in Islam. Islam prohibits homosexuality or any intimate relationship between a man and a woman before marriage (Bouhdiba, 2008). De Soudy (2016) argues that the fundamental underpinnings of those regulations come from the Quranic creation narrative of Adam and Eve. The heterosexual relationship between Adam and Eve as the first man and woman of humankind indicates and

emphasises that men are normally attracted to women and women are attracted to men. From this perspective, what is outside this sexual attachment (orientation) is considered unnatural, referred to as 'heteronormativity'. According to Connell (1987, p. 74), the heteronormativity concept refers to "heterosexuality as the taken-for-granted shape of sexual attraction". Most men in Islamic and Middle Eastern societies consider themselves as heteronormative and adopt heterosexual masculinity, which becomes a fundamental standard of their hegemonic masculinity (Aslam, 2012; Inhorn, 2012). Therefore, Jordanian Muslim men are highly likely to demonstrate heterosexual masculinity, alongside their perception of being heteronormative.

Other emotional commitments are present in Arabic Middle Eastern culture and in Islam where men can also demonstrate their masculinity. For example, men in the Middle East consider fighting for their land and protecting their women (the honour of the family) as part of their Arabic masculinity (Adibi, 2006; Aslam, 2012). From an Islamic perspective, Arat and Hasan (2018) argue that '*steadfastness*' is an aspect of masculinity that presents emotional commitment in Islam. According to them, steadfastness expresses patience, loyalty, determination, and faithfulness that come from the interpretations of Quranic verses, such as 8:45-46: "... when you encounter a company from the enemy forces, stand firm... and be patient."<sup>4</sup>, 76:12: "And will reward them for what they patiently endured with a garden in Paradise..."<sup>4</sup> and 90:4: "We have certainly created man into hardship."<sup>4</sup> The interpretations of these verses mention life as a trial for all which contains hardships where believers should be patient and steadfast. An example of this is facing the hardships of battlefields where only Muslim men are compelled to be there and remain with steadfastness and patience (Arat & Hasan, 2018; Aslam, 2012). In respect of these Arabic and Islamic emotional commitments, it is possible for Jordanian Muslim men to demonstrate masculinity through fighting, facing life's hardships with steadfastness, and protecting their families from any difficulties.

Lastly, masculinity among Jordanian Muslim men can also be constructed and presented in the symbolic dimension. A few studies indirectly indicate some of the symbols of hegemonic masculinity that are adopted by Jordanian men, such as sexual potency and stoicism (Al Momani et al., 2017; Daibes, 2011). However, other masculine symbols can possibly be adopted from their Arabic culture and Islam. For example, most Arabic Middle Eastern societies, regardless of the religious backgrounds, adopt a practice of '*Honour and shame*'. Honour and shame practices are considered as a standard rule where people and their actions

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<sup>4</sup> Saheeh International. (2012). *The Qur'an: English meanings and notes* Jeddah, Kingdom of Saudi Arabia Al-Muntada Al-Islami Trust.

can be either honoured or shamed. Some of the honour-producing actions are considered as representations of masculine symbols, such as being assertive (Aslam, 2012) or being a protector of the family (Adibi, 2006; Inhorn, 2012). Moreover, Arabic culture has defined certain ideal characteristics of what (hegemonic) masculinity of a true man, i.e., '*Rajul*', is. A real man '*Rajul*' can be signified through his strong body, sexual potency, braveness, courage, and facing death with a smile (Aslam, 2012; Inhorn, 2012). In the case of the Jordanian society, most of Jordanian men perhaps aspire and seek to meet these Arabic hegemonic masculinity symbols to present themselves as '*Rajul*', the true Arabic man.

Apart from the masculine symbols in Arabic culture, Jordanian Muslim men may also indicate the characteristics and actions of the prophets as symbols of masculinity, since the prophets were ideal men chosen by God. For example, Aslam (2012) and De Sondy (2016) outline that "taking responsibility" is a symbol of masculinity capture in the Quranic story of Adam. Other masculine symbols include the fearlessness of Ibrahim and Moses, or being the obedient of Jesus (Aslam, 2012). Even Muhammed's honesty can be considered a symbol of Islamic masculinity (Aslam, 2012). It is possible for any Jordanian Muslim man to adapt any of these Islamic symbols of masculinity to reflect his own. It is also possible for him to adapt other symbols from other cultures like Western cultures. This all depends on his personal view of his masculinity.

In all, there is a variety of possible forms and configurations of masculinity in Jordanian Muslim men that can be influenced by their Arabic culture, Islamic beliefs and regulations. There are also certainly other sociocultural factors in a Jordanian Islamic society that shape men's masculinity and can produce more forms of masculinity. So, there is an opportunity to find more forms among Jordanian Muslim men, like the participants of this study. However, this thesis at this point will try to consider how the prostate cancer experience can impact on Jordanian Muslim men and the possible forms of their hegemonic, Arabic Middle Eastern, and Islamic masculinities, which is discussed next.

#### **2.4.4 Masculinity and the prostate cancer experience**

The literature shows that the interactions between masculinity and prostate cancer experiences can begin before the diagnosis with the cancer. As previously noted in subsection 2.3.1, men may experience urinary and sexual symptoms before the diagnosis of prostate cancer. These symptoms can cause them psychological problems such as embarrassment, and feeling stigmatised, and physical problems, such as feeling weak, all of which interfere with their

hegemonic masculinity values of power and strength (Chambers et al., 2018; Chapple & Ziebland, 2002; Heyes et al., 2011). Therefore, men may ignore these symptoms, avoid talking about the issue, or hesitate to seek medical help. This has been commonly found among men from different ethnicities, such as Western whites, black Africans, and Asians (King-Okoye et al., 2017), and certainly in the Arabic Islamic world (Inhorn, 2003; Obeisat et al., 2012; Taghipour, 2009).

Prostate cancer diagnostic tests can represent a challenge to masculinity, especially the digital rectal examination (DRE) and the prostate biopsy procedure. Both tests are poorly tolerated by heterosexual men who feel uncomfortable and embarrassed by the necessary anal penetration. Many of these men with different backgrounds generally associate anal penetration with homosexuality, which therefore makes these tests a threat to their heterosexual masculinity (Broom, 2004; Evans et al., 2005; Heyes et al., 2011; Pedersen, Arnes, & Ream, 2012; Teo, Ng, Booth, & White, 2016; Winterich et al., 2009). In case of Jordanian men, Abuadas et al. (2016) and Arafa et al. (2012) found that many Jordanian men view the DRE as an embarrassing and unacceptable test. This may be because of several social, cultural and religious reasons, as outlined previously in subsection 2.3.2. But at the same time, these Jordanian men share the same view of embarrassment and discomfort from DRE as other men from different cultures. This negative view of anal penetration in DRE can be also linked with homosexuality, which again, could make this test a threat to the masculinity of heterosexual Jordanian Muslim men.

Furthermore, several studies point out that men experience diverse emotions associated with the biopsy procedure and the diagnosis of cancer. These emotions, such as pain, anxiety, uncertainty, fear of cancer and death, conflict with the ideals of stoicism and masculinity for some men (Ettridge et al., 2018; Heyes et al., 2011; Teo et al., 2016). In the case of Jordanian men, Daibes (2011) highlights that Jordanian male patients usually hide their emotions and avoid expressing pain to present their stoicism and their ability as men to tolerate pain. Thus, the emotions and pain associated with prostate cancer experiences can become a challenge to the Jordanian Muslim men, who consider stoicism to be an aspect of their masculinity.

Broader explorations reveal that masculinity interacts with the prostate cancer experience after the diagnosis as much as it does before it. In this regard, men from different cultures, such as Latino and African Americans, normally attempt to be strong in front of others after their diagnosis of prostate cancer, to maintain their masculinity (Rivas et al., 2016). Nevertheless,

the physical and psychosocial impacts of prostate cancer treatments affect their body strength and make them feel powerless. Urine incontinence and sexual dysfunctions are the most obvious examples of this. Different studies have addressed urine incontinence as a major threat to men's masculinity because of the need to sometimes use incontinence devices (adult diapers or pads), and feelings of embarrassment and lack of control over their bodies like an infant (Alexis & Worsley, 2018; Chapple & Ziebland, 2002; Ettridge et al., 2018; Hagen et al., 2007; Schildmeijer et al., 2019). Some studies, such as Berterö (2001) and Cecil, McCaughan, and Parahoo (2010) claim that incontinence has a more negative impact on men's masculinity than sexual dysfunction. In the case of erectile dysfunction, many men from different cultures feel less masculine, and subsequent feelings of shame and embarrassment when with their partners, or from other men, since potency is one of their main masculinity symbols (Alexis & Worsley, 2018; Chambers et al., 2017; Chambers et al., 2018; King-Okoye et al., 2017; Rivas et al., 2016). There have been no studies, so far, that have specifically discussed the impacts of prostate cancer treatments on the masculinity of Jordanian men, however, one study by Al Momani et al. (2017) has shown that impotency, secondary to chronic health problems, without indicating what the chronic health problems are, can be a threat to the masculinity of some Jordanian men. In this respect, the experience of sexual dysfunction may threaten the masculinity of Jordanian Muslim men who have prostate cancer, and who consider their sexual potency and performance part of their masculinity.

On the other hand, a number of studies show that men may reframe their masculinity through coping with the side effects of prostate cancer treatments and expressing acceptance of their health condition. For example, men usually accept impotency as part of the natural aging process and no doubt as a by-product of cancer treatment (Chambers et al., 2017; Ettridge et al., 2018; Evans et al., 2005). Some of these men rearrange their priorities of life and make sexuality less important (Maliski et al., 2008; Rivas et al., 2016). Others use humour, do exercises, or eat healthy diet as strategies to give positive feelings of themselves as men and to normalize their illness situation (Alexis & Worsley, 2018; Hagen et al., 2007; Langelier et al., 2019; Oliffe, Ogrodniczuk, Bottorff, Hislop, & Halpin, 2009). In Jordan, Al Momani et al. (2017) indicate that some Jordanian men with chronic diseases accept their sexual dysfunction as a result of ageing. Thus, it is possible for Jordanian Muslim men with prostate cancer to reconstruct their masculinity by accepting their sexual condition and coping with it.

Finally, several studies outline that the impact of prostate cancer experiences on men's masculinity continues after the cancer treatment. Alexis and Worsley (2018), and Chambers et

al. (2017) show that the persistence of having urine incontinence, erectile dysfunction, lack of energy, or having negative feelings such as anxiety and fear, continue threatening masculinity in the post-treatment period. The presence of these side effects and emotions have correlated with negative influences on the physical and psychosocial aspects of the life of men that consequently affect their sense of being a man. For instance, Cecil et al. (2010), Chambers et al. (2018), Evans et al. (2005), and Rivas et al. (2016) observed that many men from different cultures become unable to work or to maintain their traditional roles as protector and provider of the family due to their cancer experience, where these roles are linked with their perception of masculinity. As a result, these men feel worthless or less manly when they become unable to perform their work or maintain traditional men's tasks. This is perhaps particularly true for Jordanian Muslim men, since being a protector and provider of the family is not only a traditional role, but also an important religious task demonstrating a form of their Arabic and Islamic masculinities. So, from this point of view, the influence of their prostate cancer experience on their masculinity may be more significant.

For a better understanding of how prostate cancer experience has a negative influence on identity as a man, I integrate Connell's model of the structure of gender relations with the prostate cancer experience. This is explained in the next subsection.

#### **2.4.5 Reflecting Connell's model of gender relations with prostate cancer experience**

To return to Connell's model of gender relations, it is possible that prostate cancer experiences can affect the four dimensions where masculinity is constructed and expressed: power, production, emotional, and symbolic. Maliski et al. (2008) argue that the prostate cancer experience affects men's masculine identity by its influences on the dimensions where their masculinity is dynamically constructed.

The dimension from this illness experience most affected is the power dimension where men's hegemonic masculinity is usually demonstrated. As mentioned earlier, there are many places through the prostate cancer experience that interfere with men's hegemonic masculinity, beginning with the embarrassment from pre-diagnosis symptoms, the emotions associated with the prostatic biopsy and the diagnosis with the cancer, and later the influence of cancer treatment on men's independence, physical strength and the ability to control their bodies (Alexis & Worsley, 2018; Chambers et al., 2018; Chapple & Ziebland, 2002; Ettridge et al., 2018; Heyes et al., 2011; Maliski et al., 2008; Oliffe, 2006; Rivas et al., 2016; Schildmeijer et al., 2019).

Maliski et al. (2008) maintain that the prostate cancer experience also affects the production dimension (gender division of labour) through its impact on men's ability to maintain their traditional roles as a man. As mentioned earlier, for many men from different cultures including Jordanians, their role is to be the main source of income and protector of the family. But prostate cancer can create hardships and difficulties for men to maintain these roles. Inability to maintain these roles means that they may not be able to perform this form of their masculinity (Rivas et al., 2016).

The emotional dimension can also be impacted from the prostate cancer experience. In this dimension, sexual desire and attachments are a place where men perform their hetero/homosexual masculinity. Their masculinity from this aspect is affected as a result from the significant changes or decline on men's sexual desire and relationships with their partners, which has also been addressed in many studies, such as reviews of Alexis and Worsley (2018), Chambers et al. (2017), and Rivas et al. (2016). Moreover, Maliski et al. (2008) add that the influence of prostate cancer experiences on the emotional dimension can also come from its impact on men's emotional strengths and their ability to support and protect their families. This again can affect the power and production dimensions in term of showing strength and maintaining the protector role.

Lastly, prostate cancer experience may affect the symbolic dimension by threatening masculine symbols for some men where their masculinity is signified. As mentioned earlier, potency and stoicism are examples of masculine symbols for many men from different backgrounds including Jordanians. Hence, their prostate cancer experiences threaten their masculinity in this aspect by causing impotency, challenging their stoicism, and even by altering their perceptions of body image, like penis length (Appleton et al., 2015; Chambers et al., 2018; Ettridge et al., 2018; King-Okoye et al., 2017; Oliffe, 2006).

In addition to the discussion about masculinity and the prostate cancer experience, this subsection shows how Connell's model of gender relations is useful as a theoretical framework in this study. This model has helped so far in exploring possible forms of hegemonic, Arabic, Middle Eastern, and Islamic masculinities that perhaps are visible among Jordanian Muslim men, which can later explain how their prostate cancer experiences would impact on their gender identity. Nevertheless, this study also aims to understand the men's experiences in terms of what the possible impacts and challenges these men face and how they respond to them. Thus, this research still needs further theoretical frameworks that comprehensively help in

understanding the prostate cancer experience among these men. The literature, especially in narrative studies, has a range of tested theories and concepts that have been used to understand illness experiences. Two theoretical concepts i.e., ‘biographical disruption’ and ‘liminality’ have been used in several studies to understand cancer experiences including prostate cancer. Therefore, I have added these two theoretical concepts that can express the possible impacts and challenges of this cancer experience on these men’s bodies, their lives, their identity in general, and how they would manage these. These are discussed next in section four of this chapter.

## **2.5 Section four: illness narrative and theoretical concepts**

Prostate cancer experiences can be revealed through stories of men with this illness. Kleinman (1988, p. 49) called the illness narrative “a story the patient tells, and significant others re-tell, to give coherence to the distinctive events and long-term course of suffering”. Studying this type of narrative can reveal how patients perceive their illness, treatment, and how they cope and adjust to their suffering and illness situations (Holloway & Freshwater, 2007). Many scholars have studied the illness narrative and developed theoretical concepts that help in studying and understanding how illness is experienced and managed. I chose ‘biographical disruption’ from the work of Bury (1982, 1991, 2001) and ‘liminality’ from the work of Little, Jordens, Paul, Montgomery, and Philipson (1998) to frame the approach I took to the illness narratives of the participants in this study. Both works provide a powerful theoretical framework for understanding the prostate cancer experience among Jordanian Muslim men as well as for analysing their stories with this disease.

### **2.5.1 Biographical disruption**

The concept of biographical disruption was developed by Bury (1982) in studying the illness narrative of people with rheumatoid arthritis. Bury described the onset of chronic illness as an event that brings pain, suffering, and the idea of death, which cause a disruption to one’s biography, and his/her expected life trajectory. Bury (1991) maintained that this biographical disruption can be managed by ‘adaptation’, which can be done through ‘coping’ and ‘strategy’. In more details about adaptation, Bury defines coping as “the cognitive processes whereby an ill person learns how to tolerate the effects of illness and to maintain a feeling of personal worth” (Bury, 1991, p. 460). In 2001, Bury cited normalisation as a form of coping that can be achieved in two ways. The first form of normalisation is that patients may continue their lives with pre-illness lifestyles and keep their identity intact by maintaining their life’s activities as

much as possible, and by minimising symptoms. The second form of normalisation can be through changing the lifestyle to adapt to the new illness situation so that this new lifestyle becomes normal (Bury, 2001). Bury (1991) added that managing (adaptation) of illness disruption can also be by strategy, which refers to the actions an ill person takes or does in response to the disruptive effects of illness. Any action taken to mobilise resources in a wider social environment and maximise favourable outcomes is a strategy. A strategy or strategic management of illness is flexible, and can be altered over time, depending on a person's viewpoint, material and cultural contexts (Bury, 1991).

The concept of biographical disruption concept has been used to understand the experience of many illness, such as stroke (Faircloth, Boylstein, Rittman, Young, & Gubrium, 2004), multiple sclerosis (Green, Todd, & Pevalin, 2007), and different types of cancers including prostate cancer (Cayless et al., 2010; Hubbard & Forbat, 2012; Hubbard, Kidd, & Kearney, 2010; Neris, Leite, Nascimento, García-Vivar, & Zago, 2020; Reeve, Lloyd-Williams, Payne, & Dowrick, 2010; Trusson, Pilnick, & Roy, 2016).

Cayless et al. (2010), Hubbard and Forbat (2012), and Neris et al. (2020) have used Bury's concepts to show that prostate cancer and its treatments have disruptive effects on men's bodies, the physical and psychosocial aspects of their lives, besides their masculinity. These findings match the findings of the literature discussed in section two and three of this chapter. For example, the side effects of prostate cancer treatments, in particular sexual and urinary problems, are major visible disrupters of men's bodies that create other unsettling physical and psychosocial effects on their lives (Cayless et al., 2010). As a result, the significance of these disruptive effects on some men can change how they internally and socially view themselves, such as from being active, independent, healthy men to the opposite (Cayless et al., 2010; Neris et al., 2020).

Cayless et al. (2010) and Neris et al. (2020) also demonstrate how men with prostate cancer may face and manage the disruptive effects of their cancer experience in line with Bury's concept of adapting. This can be through accepting their illness and employing different types of strategies. For example, some men having incontinence issues limit their social activities or adopt a new social lifestyle that matches their physical ability (Cayless et al., 2010). In respect to the disruptive effect on men's identity, Hubbard and Forbat (2012) indicate that the disruption from the cancer experience has not necessarily changed the sense of self to negative as some adapt to this illness experience and reformulate their sense of themselves as positive.

### **2.5.2 Liminality**

Liminality is another concept used in understanding illness experiences among people with cancer. This concept was first used by Van Gennep in 1960 study of “the rites of passage”, which later has been adapted to describe the experience of disorientation, a sense of loss, and uncertainty among people with cancer (Blows, Bird, Seymour, & Cox, 2012; Little et al., 1998). There are two stages of liminality described as being part of the cancer experience: acute and sustained liminality. Acute liminality is the initial stage that starts when a cancer patient experiences dread, and uncertainty after he/she hears the news of his/her diagnosis. The next stage is sustained liminality, which comes after a variable of time from the acute stage when cancer patients are aware of their cancer status (Little et al., 1998). In this stage, the patients’ experiences can move at times towards acute liminality or towards a kind of ‘resolution’. This depends on many factors, such as the medical information, and the presence or absence of symptoms (Little et al., 1998).

The liminality concept has been used as a framework in studying and understanding the experience of prostate cancer, which shows that men with this illness face the two stages of liminality along with their cancer experience (Cayless et al., 2010; Neris et al., 2020; Pietilä, Jurva, Ojala, & Tammela, 2018). The acute liminality stage is presented when men discover their prostate cancer and when this makes them experience fear, feel disoriented and uncertain about their lives. The sustained liminality is also present in their experiences, for example, as a result of the negative effects of cancer treatments on their lives, or from their concerns about the recurrence of cancer in future. However, Cayless et al. (2010) highlight that men can manage the liminality status by reaching resolution, in the same way of managing the biographical disruption through coping and strategy.

In respect of the impact of prostate cancer experience on men’s identity, the concept of liminality has also been used to describe their identity status during this illness experience. Navon and Morag (2004) found that the influence of prostate cancer treatment on men’s bodies, especially their sexual function, creates a liminal state (disorientation) for these men to classify themselves as men in their society. Neris et al. (2020) add that liminality describes the transition of men’s identity, such as from healthy men to wrecked men, due to the significant influences of the cancer experience on their bodies and the physical and psychosocial aspects of their life.

### **2.5.3 Theoretical framework: biographical disruption and liminality**

The concepts of both biographical disruption and liminality have been successfully adopted in studying and understanding the prostate cancer experience. They will be particularly useful as conceptual frameworks for this research study geared towards understanding the prostate cancer experiences among a sample of Jordanian Muslim men, which will cover the study's aims.

The concept of biographical disruption could help in understanding and exploring the possible disruptive effects and challenges of the prostate cancer experience on these men's bodies and the different aspects of their lives. At the same time, it could define how these men would manage these disruptive effects and challenges of this illness experience. In addition, this concept can help in capturing two possible forms of the prostate cancer experience. The first possible form is that the experience has a significant disruption on a man's biography and everyday life, which can negatively change his sense of himself, and deconstruct his identity. The second possible form of this illness experience is that a man manages and adapts to the disruption from his cancer experience to a level where he maintains the self or reconstructs his identity. Hence, adopting this concept could give a wider and a comprehensive understanding of the influences of the prostate cancer experience on Jordanian Muslim men's identity in general, as well as its influences on all the aspects of their lives (physical, physiological, social, and religious).

In addition to biographical disruption, adopting the concept of liminality to help frame the methods will extend the understanding of the influences of the prostate cancer experience on some Jordanian Muslim men. As discussed in section two of this chapter, in general, men do experience disorientation and uncertainty in many places through their prostate cancer experiences, especially at the time of diagnosis and after treatment when they are concerned about recurrence of their cancer. Jordanian Muslim men may also experience the same form of disorientation and uncertainty through their experiences with prostate cancer. Hence, the concept of liminality helps in capturing this form of the prostate cancer experience. Adding to that, this concept may explain more about the identity status of the participants of this study with their prostate cancer experience, which supports the biographical disruption concept in understanding the impacts of this cancer experience on the identity of these men.

Furthermore, liminality has the important function of leading to resolution, which according to Little et al. (1998) postulates that cancer patients may reach a resolution after liminality,

depending on the stability of their cancer situation, the absence of complications to cancer treatment, and how they manage their illness. In a story structure, the term resolution is also commonly used where the main plot climax of the story is resolved as well as when it informs the audience how the story ends (Flanagan, 2018; Patterson, 2013). In this case, the concepts of resolution and liminality would help to define the end of the participants' prostate cancer stories whether it would be as a resolution or in a liminal space.

Although biographical disruption and liminality are Western concepts, I consider that both are useful theoretical concepts and part of the framework of this study, studying and understanding the prostate cancer experiences among a sample of Jordanian Muslim men. Again, the biographical disruption concept can help to understand the influences of the prostate cancer experience on the different aspects of their lives, and how it can affect their sense of themselves. In the meantime, the liminality concept can expand the understanding of these influences through explaining more about the experiences of uncertainty, disorientation, and identity status during the cancer experience. Both concepts can indicate two possible ways of experiencing prostate cancer. On one hand, some of Jordanian Muslim men with prostate cancer may face and experience different kinds of challenges, disruptive effects, and liminality that affect their biography and everyday life. The significance of this form of the cancer experience is a general influence on their sense of themselves as Jordanian Muslim men. On the other hand, these men may positively respond to these challenges, and manage the disruption and the liminality of their cancer experience through adaptation (coping and strategy). In this case, these men would reach a kind of resolution of their illness experience or would have reconstructed their identity.

## **2.6 Conclusion**

This chapter has acknowledged that the experience with this cancer is full of challenges, which Jordanian Muslim men may face. These challenges can be specific to those Muslim men since this cancer experience has interactions with their Arabic culture, and Islamic rituals and beliefs.

The chapter also shows that this cancer experience can possibly challenge the masculine identity of Jordanian Muslim men. By reflecting Connell's works and model of the structure of gender relations with prostate cancer experience, this cancer experience can negatively affect their sense of being a Jordanian Muslim man by impacting their bodies and on possible forms of their Arabic, Middle Eastern, and Islamic masculinities.

Besides Connell's model of gender relations, the chapter has discussed two theoretical concepts (biographical disruption and liminality) that will be used in this research to provide a wide, comprehensive understanding of the prostate cancer experience in terms of what the possible impacts and challenges on those men's everyday life are and identify how they respond to them.

The next chapter describes the methodology used. I will show how I chose the research methodology, and integrated Connell's model and the two theoretical concepts with the study's design to cover the study objectives.

# **CHAPTER 3: METHODOLOGY AND RESEARCH PROCESS**

## **3.1 Introduction**

This chapter presents the methodology and research method used in this study. It has two main sections. Section one discusses how I chose the methodology and constructed the research design for this study in five steps. I start with a discussion about the philosophical approach underpinning the study. Then, I describe the choice of methodology. The discussion continues with the steps in choosing the narrative research approach, the means of data collection, and lastly the narrative analytical approaches for data analysis. The section finishes by highlighting issues associated with undertaking a narrative analysis of (Jordanian) Arabic text.

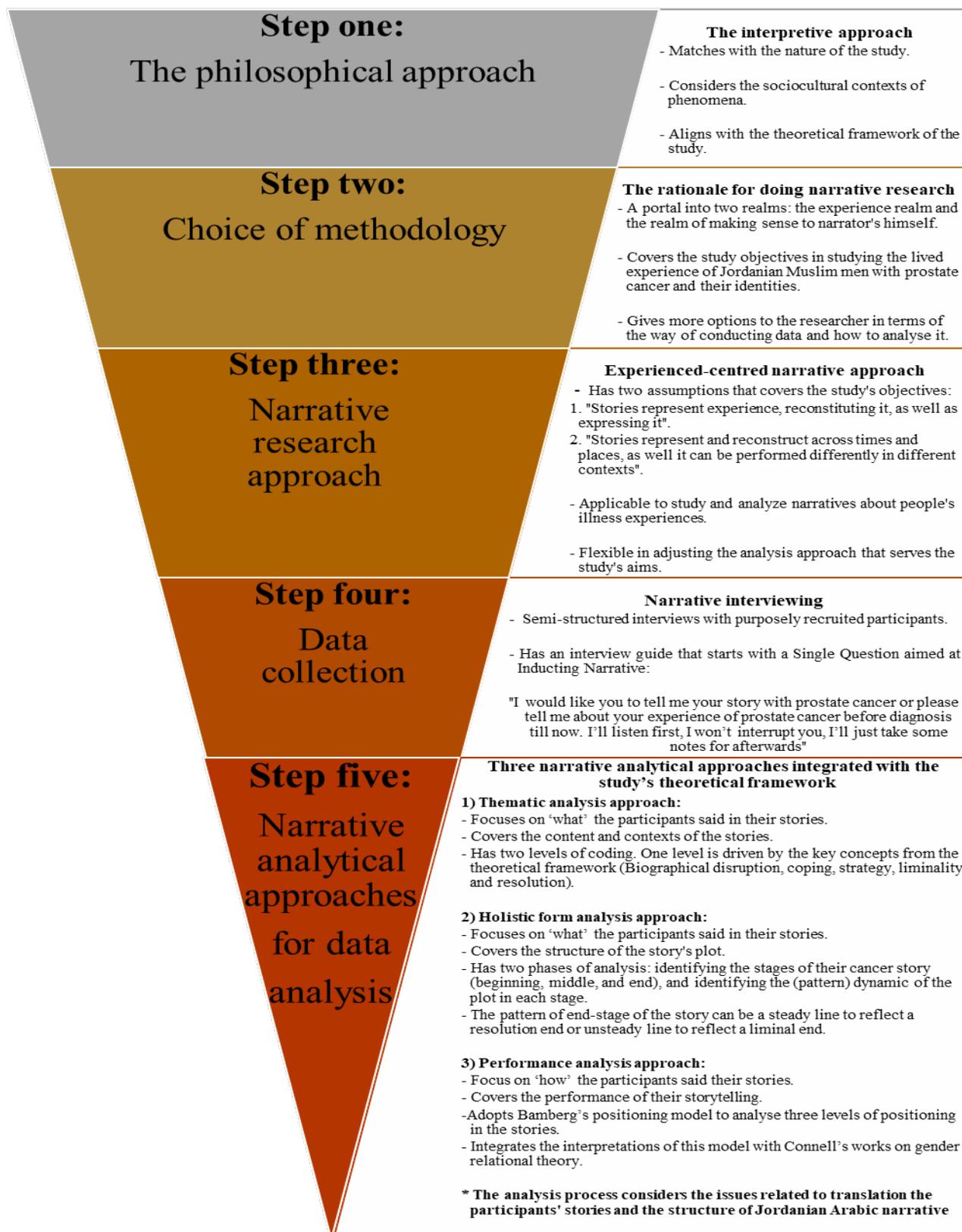
In section two, I describe the research process of the study and how it took place. I begin by explaining the research setting and gaining access to candidates for the study. I continue by explaining how the study met and maintained the ethical requirements through the research process. Then, I show how I undertook sampling and interviews of the participants. After that, I discuss data management, which includes the steps of transcribing the interviews, the analysis process, and presenting the findings. Lastly, it presents how the study maintained the research trustworthiness through reflexivity, subjectivity, and credibility in the research process.

## **3.2 Section one: research design and methodology**

This section presents how I chose the methodology and developed the research design of this study in five steps. The diagram in Figure 2 summarises these steps.

### **3.2.1 The philosophical approach: the interpretive approach**

I used an interpretive (post-positivist or constructivist) philosophical approach for this study. According to Francis, Chapman, and Whitehead (2016), this approach is flexible as it considers reality not to be fixed but constructed according to situations and contexts. They also add that phenomena being investigated under this philosophical approach may have different possibilities and meanings depending on the situations and contexts around those phenomena. Using an interpretive approach enabled me to consider sociocultural contexts and factors that influence the experience of prostate cancer among a sample of Jordanian Muslim men, which can provide different possibilities and meanings about this type of experience. This approach helped the study have a broad and reliable understanding of the prostate cancer experiences among these men.



**Figure 2: Diagram of the study's research design and methodology**

In addition, an interpretive approach is commonly used in qualitative nursing research that aims to describe, explore and generate meaning of phenomena within a social or practical context

(Francis et al., 2016). This again matches with the nature of the study and with its aims, since the study is an exploratory study which aims to understand the experiences of prostate cancer among Jordanian Muslim men within their sociocultural context.

Moreover, the interpretive (constructivist) philosophical approach aligns with the theoretical framework of this study, especially in terms of studying and understanding the impacts of prostate cancer experiences on the gender identity of Jordanian Muslim men. As noted in section three of Chapter 2, identity and gender have been studied and discussed through a branch of constructivist philosophy— social constructionism. Social constructionism holds that both gender and identity are constructed through social interactions (relations) between people and can have many representations and forms as it is influenced by sociocultural discourse (factors) as opposed to being innately grounded in biological reality (Burr, 2015; DeLamater & Hyde, 1998). Connell (2002, 2005) has adopted this philosophical approach and developed a model of gender relations to understand and distinguish forms of masculinity in any society. I have used Connell's model as a framework to discuss and explore how some of the possible features of masculinity of Jordanian Muslim men are constructed and may be affected by their prostate cancer experience. This, again, indicates how interpretive (constructivist) philosophical approach is well suited to this study as it supports the study's theoretical framework in capturing a better understanding of the experiences of prostate cancer among Jordanian Muslim men.

### **3.2.2 Choice of methodology: the rationale for doing narrative research**

Narrative is a portal into the realm of experience, where speakers lay out how they as individuals experience certain events and confer their subjective meaning onto these experiences (Bamberg, 2012). In nursing health research, narrative provides a nurse-researcher with a window to understand people's lives, as their stories represent their health-related experience with all its accompanying drama, significance and impact (Holloway & Freshwater, 2007).

Narrative research can also help understanding of how gender and identity of a Jordanian Muslim may be affected by their prostate cancer experience. It pays attention to the complexity of language and the meaning beyond the language (Squire, Andrews, & Tamboukou, 2013). Here, narrative is a portal into another realm beside the realm of experience, which is the space where a narrator attempts to make sense to him/herself (Bamberg, 2012). From this philosophical position, narrative has been used in nursing health research as a way to

understand the gendered and cultural positions of the narrator (Holloway & Freshwater, 2007). An example of this is the study by Riessman (2003) of two men with multiple sclerosis, which shows how these two men constructed and performed their gender identity as they were telling their stories about their illness. In the case of this study, narrative research allowed me to examine the gender identity of Jordanian Muslim men as they told their stories about prostate cancer. Through this research, I can focus on how they construct their gender identity, the roles that they see men holding in general, and themselves. Thus, narrative research methodology offers the researcher more chance to explore, study, and understand the experiences of Jordanian Muslim men with prostate cancer as well as their gender and identity.

Finally, adopting narrative research as a methodology for this study gave me more options in terms of how to collect data, and how to analyse it. Holloway and Freshwater (2007), Joyce (2015) and Riessman (2008) introduce different ways of collecting narrative data in health research, such as interviews, focus groups, or visual observations, and different approaches of analysis, like thematic, content, structural, and performance analysis. This gave me as a researcher more flexibility in the ways of collecting the data and combining different analytical approaches that meet the study questions and objectives. More will be discussed later in the subsections on data collection and narrative analysis.

### **3.2.3 Narrative research approach: experience-centred narrative approach**

There is a range of narrative methods available for use. According to Squire et al. (2013), nearly all narrative research fits into one of three main approaches: Labovian, experience-centred, and socioculturally-oriented. For this study, the experience-centred narrative approach was chosen for two main reasons.

The experience-centred narrative research approach has two assumptions that serve the study and its objectives. The first assumption is phenomenological, which means “narratives (stories) represent experience, reconstituting it, as well as expressing it” (Squire, 2013, p. 48). This means that the experiences of Jordanian Muslim men with prostate cancer can be expressed and represented through their stories about this illness (illness narratives). The second assumption is that narratives (stories) represent and reconstruct across times and places, as well as being able to be performed differently in different contexts. It means that there are multiple truths of an individual’s story and it can be shaped by social and cultural contexts (Squire, 2013). Hence, this assumption also serves the study by considering the Jordanian and Islamic sociocultural contexts in the stories of men with prostate cancer.

The experience-centred narrative research approach is more flexible than Labovian narrative approach in terms of the type of data to be studied and the way of analysing it. Patterson (2013) highlights that the Labovian model analyses the structure of narrative via six fundamental elements: the abstract, orientation, complicating action, evaluation, resolution, and coda. In the case of this study, the structure of Jordanian Arabic text is different from English, which would have made it difficult to find the six elements of the Labovian model in this type of text. Therefore, the Labovian narrative approach and its analysis model may not be applicable for the stories of the participants in this study. In addition, Patterson (2013) and Riessman (2008) indicate that not all narrative, especially narrative about traumatic experiences, contains the six elements of the Labovian model. Using this model with this type of narrative data may lead to the loss of the meaning of that experience. This, again, makes it a difficult and unwise challenge to use the Labovian narrative approach in this study.

Unlike the Labovian narrative research approach, the experience-centred narrative approach has been used in health research to study and to analyse people's narratives about trauma and illness experiences (Casey, Proudfoot, & Corbally, 2016; Squire, 2013). The applicability of this research approach to studying this type of narrative makes it suitable for the stories of Jordanian Muslim men with their experiences of prostate cancer. However, one limitation of using an experience-centred narrative research approach is that this approach focuses more on experience than on the significance of language. So, researchers using this approach may neglect the connection between interpersonal and cultural forms of language, which may lead to misinterpretation of the related narrative (Squire, 2013). To overcome this, and to reduce the possibility of misinterpretation, one must consider language features in the analysis process, such as metaphors and the tone of the collected narrative (Casey et al., 2016). In the case of this study, I added part of a performance analytic approach to cover what can be neglected of the language in the narrative analytic approaches of others. (See the narrative analysis subsection below).

#### **3.2.4 Data collection: narrative interviewing**

The fourth step in developing my research design for this study was to decide how to collect the stories of participants with prostate cancer. In qualitative nursing research, and narrative research in particular, the interview is one of the most common methods of data collection (Holloway & Freshwater, 2007; Joyce, 2015). In terms of collecting stories, Holloway and Freshwater (2007) indicate that 'narrative interviewing', which is the method of interviewing to collect stories, should not have a rigid structure or focus on a single issue. They recommend

that narrative interviews should have a small number of opened-ended questions to minimise interruptions of the thread of telling a story. This way of interviewing matches with the way of experience-centred narrative research interviewing method, which is to do semi-structured interviews to collect stories (Squire, 2013). Thus, this study has used semi-structured interviews as a method to collect the participants' prostate cancer stories.

To undertake this type of semi-structured interviews, it was important to develop an interview guide that allows the participants to tell their stories without any interruptions, and without using prompts which might add an unintended shape to their narrative. Therefore, the interview guide of this study used the Biographical Narrative Interpretative Method (BNIM) interviewing technique, which starts with a Single Question aimed at Inducing Narrative (SQUIN) (Wengraf, 2001). The question I used is:

I would like you to tell me your story with prostate cancer—in detail—from before diagnosis till now. I will just listen. I will not interrupt you. I will just take some notes for afterwards.

Narrative interviewing is thus conducted by inviting the participants to answer that single question and to tell their stories in their own way without interruptions. At the same time, this way of interviewing keeps the power balance between the interviewer (me) and the participants (Esin, 2011). This power balance during interviewing is an important point for trustworthiness of this study (see the research trustworthiness subsection in section two of this chapter). And finally, the interview guide for this study also included a few open-ended questions to keep the flow going. The questions were asked only when the participant seems to have exhausted everything that he wants to talk about.

### **3.2.5 Narrative analytical approaches for data analysis**

Experience-centred narrative research usually uses a thematic analytic approach (Squire, 2013) or Murry's framework of analysis (Casey et al., 2016) to analyse people's stories of their illnesses. However, I use the works of Riessman (1993, 2005, 2008) on illness narrative analysis to guide my choice of analytic approaches for the study. According to Riessman (2005), the choice of analytic technique should be connected to the information the research hopes to extract. If the narrative researcher is most interested in the events and the experiences of individuals, then the analysis should focus on the content of a text and what is said (Riessman, 2005). This can be achieved through doing content or thematic analysis (Holloway & Freshwater, 2007; Riessman, 2005). If the narrative researcher is most interested in social order, social process, culture, and identity, then the focus of analysis is more on how the story

has been constructed and how it transmits in wider socio-cultural meanings. This can be completed through structural or performative analytic approaches (Esin, 2011; Riessman, 2005).

In the case of this study, the focus is on both the content and on identity as it aims to study the experiences of prostate cancer from Jordanian and Islamic contexts, as well as the impacts of this experience on gender and identity. Therefore, the study needs different analytic approaches that consider the structure, content, and context of the stories of participants with prostate cancer, to cover the objectives of the study. I have combined three narrative analytic approaches: thematic, holistic form, and performance analyses; and integrated them with the theoretical framework of the study to give strength and depth in the analysis of the participants' stories.

#### *3.2.5.1 Thematic narrative analysis approach*

The analysis begins with transcribing the participants' oral narratives (Riessman, 1993). Then, there is reading and re-reading, to be familiar with the data and to write down initial ideas that emerged from the reading (Braun & Clarke, 2006). The next steps are coding and searching for themes (Braun & Clarke, 2006; Riessman, 2008). According to Braun and Clarke (2006), searching for themes can be, and in this case is, driven by the researcher's theoretical or analytic interest. It can also be semantic where the themes are identified within the superficial meanings of the data, or be latent where the themes are identified within broader meanings found in the data (Braun & Clarke, 2006).

There were two levels of coding. The first level of coding was driven by the key concepts from the study's theoretical framework (biographical disruption, coping, strategy, liminality, and resolution). This level of coding was supported by a second level that considered the context, and my own interpretations of the data. Both levels help to capture what the participants say about their prostate cancer experience in terms of the impact on, and challenges to, their lives and identity, as well as how they have or have not adapted to the experience. More explanation about coding with examples will be discussed in section two of this chapter under the data analysis subsection.

#### *3.2.5.2 Holistic form analysis approach*

As thematic narrative analysis focuses on the content and context of the participants' stories, holistic form analysis focuses on the structure of the story plots. This approach examines what the participants said to define the structure of the story plot and then explains its patterns

through graphs. According to Tuval-Mashiach (1998), this process of analysis goes through two phases: identifying the plot axis and identifying the dynamic of the plot.

In the first phase, the researcher identifies how the plot develops in each stage of the story (the beginning, middle, and end). This involves analysing how the events are connected in the story to get a clear and persuasive storyline (Smith & Sparkes, 2015). The research here focuses on the course or direction of the event (the content of a story) for development of the plot axis rather than the event itself (Tuval-Mashiach, 1998). The second phase of analysis identifies the dynamics of the plot, which can be derived from the participants' reflections on each stage of the story, such as forms of speech, and expressions of emotions (Tuval-Mashiach, 1998). The two phases of analysis are reflected through a graph that presents a storyline and the patterns of its plots. A graph can have a steady line  $\text{-----}$ , a progressive pattern  $\text{/}$ , a regressive pattern  $\text{\}$ , or a combination of these patterns (Tuval-Mashiach, 1998). In steady line examples, a graph shows that the plot is steady and does not change with the storyline, while in a progressive pattern the plot develops over time with the storyline (Tuval-Mashiach, 1998). On the other hand, a regressive pattern indicates a course of deterioration or decline of the plot over time with the storyline (Tuval-Mashiach, 1998).

After having produced graphs, the researcher may continue the analysis to build a typology of the participants' stories. This can be through clustering the stories that have the same graph shape (Smith & Sparkes, 2015). Tuval-Mashiach (1998) indicates that graphs do not necessarily represent the classic narrative typologies (i.e., genres), such as romance, comedy, or tragedy. In illness narratives, Robinson (1990) suggests three typologies through graphs: 'processive narrative', 'regressive narratives', and 'stable narratives'. Others classify different types of illness narratives that may not only be based on the narrative structure but also based on its contents and contexts, such as 'contingent narratives', 'moral narratives', and 'core narratives' (Bury, 2001), or 'restitution narratives', 'chaos narratives', and 'quest narratives' (Frank, 2013). However, I did not adopt these suggested typologies in this study to avoid enforcing these possible typologies in stories of participants with prostate cancer.

In this study, the analysis of the holistic form approach focuses on the structure of the prostate cancer story plot of the participants. So, the first phase of analysis is to identify the plot axis of each participant's story, which can be established through the timeline of the story and how events are connected. The second phase of analysis is to identify the dynamic (pattern) of the story plot, which depends on the participant's reflections on each stage of his story (beginning,

middle, and end). In this phase, I consider two possibilities of the story's end: a resolution end or a liminal end (space). A resolution end indicates the participant's reflections on the stability of his illness and on living his life as normal. A steady line ----- is the pattern to represent this end. On the other hand, a liminal end or liminal space indicates a participant's reflections on the instability of his illness and on his experience of uncertainty. So, I have added an unsteady line ~ as a pattern to represent this end.

After completing the first and the second phases of holistic form analysis, the structure of the participant's story plot is presented in a graph. There is, therefore, a graph for the story of each participant. The next step of analysis is to find the similarities and differences between the graphs to identify the typology.

By adopting the holistic form analysis in this study, an overview of the participant's story plot is created, and it is possible to look for commonalities amongst the participants' stories to identify the typology. This supports the application of thematic analysis as this type of analysis is useful in finding the similarities and differences among stories.

### *3.3.5.3 Performance analysis approach: Bamberg's positioning model*

Unlike thematic and holistic form analysis, this analytical approach focuses on how the story is co-constructed and the influence of the researcher, other listeners, and the social circumstances on the performance of storytelling (Riessman, 2008). In this approach, the researcher may concentrate his/her analysis on the dialogue between characters in a story, on their positioning in that story, and/or on the audience responses to storytelling (Riessman, 2005). Deppermann (2019) and Esin (2011) highlight that analysing the positioning of a narrator, other characters, and/or the audience in a story is suitable for studying their gender or identity construction. Therefore, this study focused more on analysing positioning of the participants in their stories to study their identity, particularly gender identity, and to examine how it has been affected by their prostate cancer experiences.

An example of positioning analysis is Bamberg's positioning analysis model. This model analyses positioning in stories in three levels (Bamberg & Georgakopoulou, 2008). Level one is analysing positioning on the level of the story: 'How are the characters positioned in relation to one another within the reported events?'. Level two analyses positioning on the level of the interaction: 'How does the speaker position him/herself to the audience?'. Level three is analysing positioning on a wider level including sociocultural dominant discourses (master

narratives) in the story: ‘How the speaker/narrator positions a sense of self/identity with regards to dominant discourses or master narratives’ (Bamberg & Georgakopoulou, 2008).

In the case of this study, the three levels of analysis are as follows:

- Level one is to analyse how a participant positions himself in his prostate cancer story, especially in relation to prostate cancer and its experience.
- Level two has two parts. The first part is to analyse how the participant positions other characters and how the other characters position him in the story. The second part is to analyse how the participant positions me as his audience.
- Level three is to analyse how the participant positions himself with the dominant discourses raised in his cancer story, particularly the discourses related to masculinity.

The changes of the participant’s positionings in the three levels may reflect the impacts of the prostate cancer experience on his gender identity. To strengthen this analysis model and my interpretations of the participant’s positionings, I integrated Connell’s model of the structure of gender relations discussed in section three in Chapter 2.

### **3.2.6 Narrative analysis of (Jordanian) Arabic text**

The participants of this study told their stories with prostate cancer in Jordanian Arabic language. Narrative analytical methods have mainly been developed by Western scholars, where some of these methods have been translated into Arabic. Some Arabic researchers adopt these translated analytical methods to analyse Arabic texts, but what has been adopted is that Arabic text is translated to English and then the English text is analysed using narrative analysis approach/es, such as the thematic analysis approach in the studies of Zeilani and Seymour (2010, 2012) on illness stories of Jordanian Muslim women. This approach is possibly due to a non-Arabic researcher being involved in the analysis process, or because it is part of the requirements of the research and publications. In my case, my supervisors are English speakers, and I wrote my thesis in English as a requirement of the University. Thus, the translation of Arabic text was needed in this study and that led to the emergence of another issue, which is the challenge of translating (Jordanian) Arabic narrative text.

In respect to translating challenges of (Jordanian) Arabic narrative text, I reviewed the recommendations and considerations of Al-Amer, Ramjan, Glew, Darwish, and Salamonson (2016). According to this group, there are three challenges in translating Arabic narrative data to English in qualitative health research. The first challenge is the linguistic structural differences between Arabic and English. The group give an example through the work of Bach

(1967) which shows Arabic does not have a present perfect tense. To solve this challenge, Al-Amer et al. (2016) advise that translations are managed through a translator who shares the study participants' language and culture. The second challenge is the translation of metaphors which may impact on their cultural meaning. Thus, Al-Amer et al. (2016) recommend keeping metaphor statements unchanged and then explaining them by rephrasing its words to capture the intended cultural meaning. The last challenge is understanding medical terminology. Here, Al-Amer et al. (2016) give an example of a patient describing a health term of "fasting blood sugar" as "my sugar while my stomach was empty". So, they also recommend underlining the patient's words and explaining what they mean.

In the case of the analysis of Arabic text, Al-Amer et al. (2016) advise conducting the analysis in Arabic language and then doing the translation at an advanced level of analysis, such as doing the translation when searching for themes in thematic analysis. Thus, the analysis in this study was conducted in Arabic language and the translation was done at a higher level of analysis. The translation was done by me, as a native Jordanian Arabic speaker, with some assistance from two Jordanian colleagues, who were doctoral students in schools of linguistics and nursing. We translated the participants' quotes to the closest meaning taking into consideration the context and cultural meaning of the text. My supervisors checked the quotes to see if they were clear to them. I added some comments in the translated quotes to help non-Arabic speakers to understand the meaning (see the quotes in the finding chapters, Chapters 4, 5, and 6).

### **3.3 Section two: research process**

#### **3.3.1 Research setting**

The participants of this study were recruited from King Hussein Cancer Centre in Amman, Jordan. This cancer centre is a non-governmental and not-for-profit cancer centre. In Jordan, most Jordanian people who get cancer, get an exemption from paying for their healthcare and cancer treatment either through the Jordanian government or donations. I chose this centre because it is the only comprehensive, specialised cancer centre in Jordan, and most cancer patients in Jordan are usually referred to it. This gave me the opportunity to find and recruit sufficient numbers of Jordanian Muslim men with prostate cancer.

#### **3.3.2 Ethical approval and considerations**

I obtained ethical approval from the ethics committees at Victoria University of Wellington and the Institutional Review Board (IRB) at King Hussein Cancer Centre, before gaining access

to the participants and performing the data collection (Appendices 2 & 3). Through this process of approval, the IRB required me to use an internal investigator and a social worker to facilitate the recruitment of the participants at the Centre. The investigator was a consultant radiation oncologist, who later assigned his nurse coordinator at the radiation oncology department to help me recruit participants from his clinic. The social worker was from a psychosocial programme at the Centre and was there to support the patients in case of any potential risk from the study. The study was fully explained to these external partners, and they agreed to help in the recruitment process for participants.

I was also aware of the ethical and legal considerations to meet the requirements of both ethical committees, which were mainly based on five ethical core principles. These five principles were maintained through the research process:

#### *3.3.2.1 Principle one: Respect for autonomy and individual responsibility*

According to Woods and Lakeman (2016), the autonomy of a study's participants is met if they freely decide to be part of the study without any coercion or external influence or restraint. Scott (2017) adds that this autonomy is also met by adequately informing the participants about the nature of the study. From this point, I maintained the participants' autonomy through the study information sheet and consent form (Appendices 4-6). Both the information sheet and consent form in this study were written in simple Arabic and English language (Appendices 4 & 5) based on the requirements of Victoria University of Wellington Human Ethics Committee and the IRB from King Hussein Cancer Centre (Appendix 6). These forms explained the study, its objectives, the risks and benefits from the study, and how the participants' rights were protected. My role was to explain these forms and to make sure that the participants understood them before they were enrolled in the study. The nurse coordinator, the social worker from the cancer centre, and I made sure that all participants were competent to consent, and that no one was vulnerable. The participants were fully informed about the process. I explained to them their fundamental right to decide whether to participate or not. When they agreed to participate, I explained again their right to withdraw from the study at any point. I also provided another opportunity for them to read the information sheet prior to the interview commencing. I opened a discussion with them about any questions they had before completing the consent forms (Appendix 5 & 6).

### *3.3.2.2 Principle two: Respect for privacy, anonymity, and confidentiality*

Woods and Lakeman (2016) and Victoria University Human Ethics Committee (2016) highlight that respect for privacy is a universal right and it is a legal, ethical requirement in human research. In Jordan, privacy is not only a legal right in the Jordanian constitution (Article 28: Right to privacy) but also a cultural value (World Legal Information Institute, 2006). In this study, I maintained the participants' privacy in two ways. The first way was by conducting interviews in a private room. The second way was by maintaining the confidentiality of their information. I protected their personal information and the collected data in a secure place accessed only by me (a soft copy on a computer locked with password, a hard copy in a locked cupboard). In addition, a confidentiality agreement form (Appendix 1) was signed by those who were given access to the data. This agreement was used in this study for those who provided translation assistance. The participants were informed and assured that the confidentiality agreement would be signed before the data was accessed.

Woods and Lakeman (2016) add that respecting participants' privacy can be through protecting their identity by anonymity. Anonymity means "no person, not even the researcher, will be able to identify individuals participating in a study" (Woods & Lakeman, 2016, p. 40). However, the nature of qualitative and narrative research makes it difficult to guarantee absolute anonymity. The researcher meets the participants face-to-face to develop rapport with them regarding obtaining information (Woods & Lakeman, 2016). In this study, anonymity was assured through use of numbers instead of using pseudonyms to identify the participants. The participants' names were also not recorded on the audio-taped interview or used in any place or stage in the study.

### *3.3.2.3 Principle three: Respect for beneficence and justice*

In this ethical principle, Scott (2017) and Woods and Lakeman (2016) indicate that justice requires fairness in dealing with research participants. Thus, justice in this study was met by treating the participants fairly through the research process, such as clearly explaining to all of them the information sheet and consent process during the data collection period. Another example of fairness in the study was in the balance of presenting their stories in the findings, regardless of whether their stories reflected negatively or positively about the prostate cancer experience. My supervisors and I were aware of the importance of achieving that balance in the participants' quotations in the findings.

Beneficence is another core principle in nursing research and practice that involves avoiding and removing potential harms from a research study (Scott, 2017; Victoria University Human Ethics Committee, 2016). In this study, it was important that the participants not feel uncomfortable. The time and place of the interview needed to be flexible and convenient for them. It was important to ensure that the interview was not prolonged so that the participant might feel too tired to complete it. Thus, I explained to the participants that they were free to stop the interview and complete it later in another session. Moreover, I was aware that relating the experience and stories with prostate cancer might be disturbing to the participants and could lead to potential harm, bringing up feelings such as anxiety, fear, and sadness. I explained to each participant prior to the interview that if he became emotional, there would be a social worker in the Centre who would provide professional counselling during and after the study. None of the participants claimed any psychological distress from the study, and this was confirmed by the social worker.

#### *3.3.2.4 Principle four: Respect for personal integrity and human vulnerability*

Woods and Lakeman (2016) and Victoria University Human Ethics Committee (2016) identify some groups of people who are more susceptible to physical or psychological harm. They are vulnerable because of a lack of knowledge, power, or competence in research contexts and processes, such as refugees, prisoners, homosexuals, children, and ethnic minorities. In this study, there was such a vulnerable participant, who was a non-practising Muslim. This might make him slightly different from the other participants. In his case, he was treated fairly, just like other participants, by my respecting his values and beliefs. His story was also presented fully like others in the findings. His case can be another example of how the study met the third ethical principle of respect for beneficence and justice.

#### *3.3.2.5 Principle five: Respect for cultural diversity*

Woods and Lakeman (2016) point out that awareness of cultural differences and respecting these differences should be considered in ethics for health research. In this study, being a Jordanian Muslim man and Arabic speaker facilitated awareness of the cultural values of the participants, who are Jordanian Muslim men. At the same time, this study was being assessed in New Zealand. So, the Human Ethics Committee from Victoria University of Wellington required acknowledgment of the Treaty of Waitangi and its three principles (partnership, participation, and protection). These three principles should be considered when the research project is performed in New Zealand, therefore, these principles were not directly applicable

to this study. However, these principles made me aware of respecting other cultures, such as Māori culture.

### **3.3.3 Sampling and recruitment**

I engaged in purposeful sampling, choosing participants on the basis of having common characteristics.

The inclusion criteria were:

- Jordanian Muslim.
- Age over 18.
- Diagnosed with prostate cancer.
- Minimal 6 months since diagnosis<sup>5</sup>.
- Radiotherapy followed by hormonal therapy.

The exclusion criteria were:

- Recent diagnosis.
- Non-Muslim.
- Cognitive impairment that would interfere with the ability to participate in the interview.

My supervisors and I decided to consider a range of 8-12 participants. This range is acceptable for a narrative study as these studies can involve large amounts of data from small samples especially when the sample is homogeneous (Holloway & Freshwater, 2007). After completing 12 interviews, the sample size of this study was eventually increased to 15 participants, as getting more stories would increase the opportunity of having rich data about the experience of prostate cancer.

After deciding the sample size and obtaining ethical approval from Victoria University of Wellington Human Ethics committee and the IRB from King Hussein Cancer Centre (KHCC), the recruitment process started. I firstly met a consultant radiation oncologist (the internal investigator), and a social worker from a psychosocial programme at the Centre. During the meeting, we discussed how the recruitment process would be followed at the Centre. We agreed to recruit the participants through the internal investigator's clinic. He nominated his nurse

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<sup>5</sup> Six months or more would be enough time for the participants to have been diagnosed and have experienced cancer treatment. So, their stories with prostate cancer can produce more data about their experiences with the diagnosis and their cancer treatments.

coordinator at the radiation oncology department as she knows his patients. Thus, I had another meeting with the nominated nurse coordinator to explain the study and what participants were needed.

In the meeting with the nominated nurse coordinator, we decided she would lead the recruitment as part of her normal work. Every day the nurse had a list of patients to be reminded about their appointment. She went through each list and checked which patients met the inclusion criteria. She then contacted the potential participants to remind them about their appointments and to tell them about the study. When the potential participants expressed their interest in participating by phone, she explained to them more details of the study as outlined in the information sheet (Appendices 4 & 6). She then gave me the person's name and the time and date of their appointment for me to meet with them. When I met a potential participant, I gave him a copy of the information sheet. I talked to him about the study to ensure his willingness to participate. Then, we discussed the suitable time for him to do the interview. I contacted participants from the nurse coordinator list individually, and all of them showed willingness to participate in the study. I was also aware and open minded of their treatment status (still on treatment or completed) and socio-economic situation, such as single, married, employed or unemployed. Considering the sensitivity of the research topic, I was in contact with the social worker from the psychosocial programme at the Centre, during and after the recruitment period. The social worker signed a confidential agreement form (Appendix 1) before checking the participants and acting as a support person if a participant experienced any psychological distress from the study. Eventually, 15 participants were recruited and interviewed between September to November 2017. All of them had completed their radiotherapy while some were still on their hormonal therapy at the time of the interview.

### **3.3.4 Interviewing the participants**

On the interview day, I sat with the participant in a private quiet room, and I offered him something to drink (a cup of tea or coffee) before we started, to make him more comfortable. I explained to him again about the study information sheet. I gave him time to read and ask any questions or express any concerns. I told him that the interview would be tape-recorded, and he could ask at any time to turn the recorder off. I also informed him that the Centre would provide a social worker in case he felt emotionally disturbed at any time during the interview. Then, I checked again that he had read and understood the information sheet before then signing the consent form.

The interview guide in Appendix 7 was followed in the interview. So, I began all the interviews with the same question, which was ‘I would like you to tell me your story with prostate cancer—in detail— before diagnosis till now. I will just listen. I will not interrupt you. I will just take some notes to use afterwards’. All the participants answered this question by describing their experience with prostate cancer from before diagnosis to their current situation, in chronological order. After the participant finished answering this question, I prompted them to elaborate on aspects they provided from answering the initial question, such as ‘You said ... can you please tell me more about what happened, how you felt’. The other questions in the interview guide were also used to get greater detail about his experience.

During the interview, I wrote my own observations while keeping my attention directed towards the participant at all times, as attentive listening is important to facilitate the telling of the story (Esin, 2011). Each participant narrated and answered the question freely without any interruption. After the participant had talked about everything he wanted to talk about, I then followed up by asking questions for further clarification or moved to another question. All the participants were comfortable and open to answering any question asked, including questions related to their sexual dysfunctions. Before stopping recording, the participant was asked if there was anything he wanted to add, to clarify, or to discuss more regarding his experience with prostate cancer. The length of recordings ranged from 35 to 65 minutes.

At the end, I thanked each participant for participating in this study. The participant was asked if he wanted a copy of the interview transcript or not. None of the participants wanted one. They were also encouraged to contact me, the nurse coordinator, or their doctor (the radiation oncologist) if there were any issues to be discussed regarding the study. None of them did so.

### **3.3.5 Transcribing the interviews**

According to Braun and Clarke (2006) and Riessman (1993), transcribing is a part of the data analysis. So, the data analysis process in this study began with transcribing the first recorded interview. I commenced ‘rough transcriptions’ as recommended by Riessman (1993), which included transcribing all words, pauses, emotions in the interviews, including my speech.

I also followed the transcription guidelines by Linguistic Data Consortium (2008) to help me to do quick rich Arabic text transcription. I began transcribing each interview by identifying who was the speaker in each segment of the conversation (the participant and me). After the segment was transcribed, the next step was to identify the sentence units in this segment. According to these guidelines, the sentence unit is identified as a cohesive group of words that

give a reasonable meaning. Standard punctuation is also added to identify the sentence unit, such as full stop, comma, question mark etc (Linguistic Data Consortium, 2008). However, it was sometimes tricky to identify a sentence unit in the participants' conversation segments as they used very complex sentences. This is very common in spoken Arabic. Thus, the sentence unit was identified where an idea from clauses was completed, as advised by the guidelines of Linguistic Data Consortium (2008). My observations and comments were also included, such as the participant's body language during transcribing. I used transcription conventions defined in the books of De Fina and Georgakopoulou (2019) and Wooffitt (2005) with some modifications. Some of the transcription conventions are outlined as footnotes in the findings chapters but all conventions are in Appendix 8.

I transcribed all the interviews in Jordanian Arabic language in Microsoft Office Word 2013. English words and medical terms in the transcript were written in English. After each transcript was completed, I reviewed it many times with the audio file to ensure it was accurate. The process was time-consuming, but at the same time, it helped me to become familiar with the data.

### **3.3.6 Data analysis**

As mentioned earlier, this study needs a multistage narrative analysis with three complementary analytical approaches (thematic, holistic form, and performance). These approaches focus on what the participants said in their stories about their experiences with prostate cancer, and how these stories were told. Thus, the analysis process was in stages that cover the steps of analysis in these analytical approaches.

#### *3.3.6.1 Stage one: analysing the structure of the prostate cancer story*

In this stage, the focus was on analysing the structure of the participants' prostate cancer stories from 'what' they said about their prostate cancer experience. Hence, this stage adopted the main steps of the holistic form approach.

The first step of this stage began with reading and re-reading the transcript of each interview, to be familiar with its content (a step of thematic analysis). The second step was to analyse how the events were connected in the cancer story to get a clear storyline (the first phase of holistic form analysis). All the participants revealed a mixture of events that happened during their life before the diagnosis with cancer, the diagnosis moments, the experience of cancer treatment, and their current illness situation. The way those participants revealed these events formed the storyline of their prostate cancer experiences. So, in this step, the events that occurred in the

early stage of the cancer experience would reflect the beginning of the cancer story, while the events unfolded in the current illness situation would be considered as the stage where the story might end. Lastly, the events in between would be the middle of the cancer story. After that, the third step of analysis began, which was to look for the patterns of the story's plot in each stage of the story (the second phase of holistic form analysis), which depended on how the participant reacted to and expressed his cancer experience in each part of his story. The patterns were identified as the following:

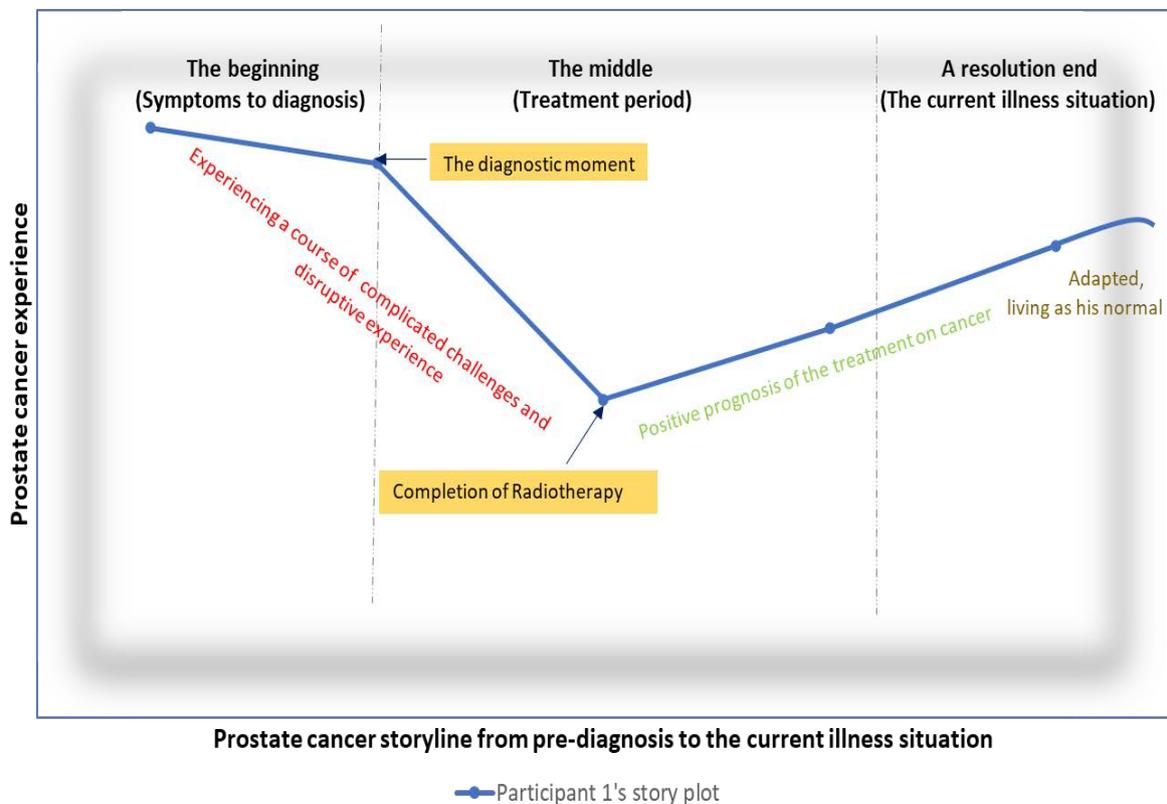
- **A regressive pattern** | \ indicates the participant's reflections to a course of complicated challenges and disruptive experience through his prostate cancer experience.
- **A progressive pattern** | / indicates the description of the experience that reflects the positive progress of the treatment on cancer and handling of the challenges and disruptive effects of the cancer experience.
- **A steady line** | --- indicates the stability of the participant's illness current situation, which can reflect his adaptation to his illness or his living with his illness as a normal state. I have considered this pattern as a resolution end of a story.
- I also added **an unsteady line** | ~ ~ as a pattern to reflect the instability of the participant's current illness situation, and the experience of uncertainty (liminality). I have considered this pattern as a liminal end of a story.

During the second and third steps in this stage of analysis, I asked the following questions to help me in mapping the storyline and tracking the participant's reflections in each stage of the story:

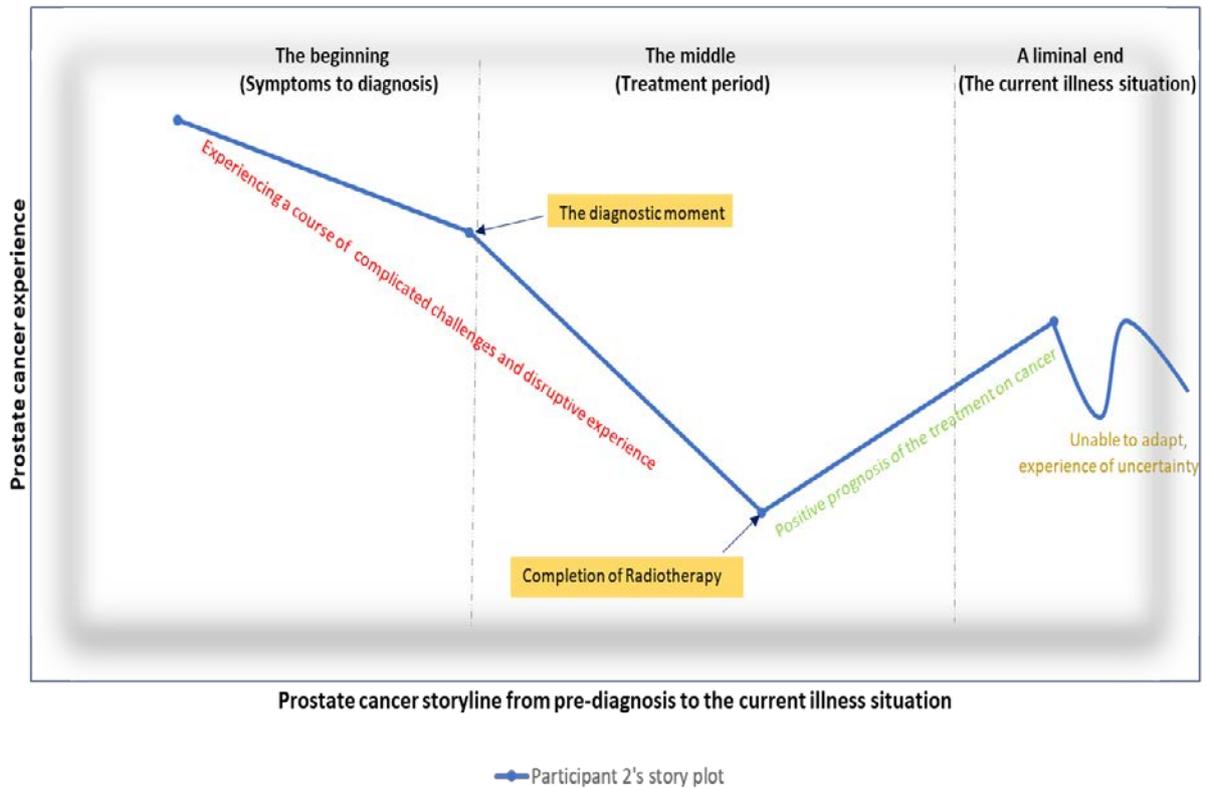
- How did the participant's prostate cancer story start? What were the pre-diagnosis symptoms that he had?
- What were the diagnostic tests he went through and how was his experience with it?
- What was the diagnosis experience— which included the diagnosis moment, the participant's reaction, and the responses of his family?
- What had happened after the diagnosis and what was his experience with his prostate cancer treatment?
- Were there life changes?
- How did he respond and react to those changes?
- What was his current illness situation and how did he express it?

After that, the fourth step was to present the structure of the participant's story plot in a graph. Each graph was a combination of different patterns (regressive, progressive, a steady line, or unsteady line). Turning points were the connection points between the patterns. Figures 3 and 4 are examples of graphs of the prostate cancer story of two participants, graphs of the participants' story plots are in Appendix 9.

The four steps of analysis were done for each participant's interview transcription, and each one's story plot was presented in a graph. The last step of this stage was to cluster the stories which had the same graph's shape and put them under one typology.



**Figure 3: The graph of Participant 1's story plot**



**Figure 4:** *The graph of Participant 2's story plot*

### 3.3.6.2 Stage two: analysing the content and context of the prostate cancer story

In this stage, the focus of the analysis was on what the participants said about their prostate cancer experience. Here, I continued the analysis process with the steps of the thematic analysis approach. Thus, this stage contained the steps of coding and searching for themes.

This stage began with doing the first level of coding. In this level, I labelled or highlighted excerpts of the interviews with the key concepts of the study's theoretical framework as follows:

- **'Biographical disruption'** is highlighted with red colour to code the data that indicate disruptive effects and challenges from a participant's prostate cancer experience or indicates a change in his identity.
- **'Coping'** is highlighted with blue colour to code the data of the participant's responses that indicate acceptance of his illness condition or normalisation of the illness.

- **‘Strategy’** is highlighted with green colour to code the data that indicates the participant’s actions to face and manage the disruptive effect and challenges from his cancer experience.
- **‘Liminality’** is highlighted with yellow colour to code the data that indicates the participant’s experience of uncertainty, deterioration, and inability to manage his current illness situation, or a transition of his identity.
- **‘Resolution’** is highlighted with dark yellow colour to code the data showing the participant’s adaptation to the current illness situation and overcoming its challenges.

This level of coding included the participant’s tone of voice, feelings, and body language. Figure 5 is an example of what the first level of coding looked like. This level of coding strengthened the analysis of stage one as it supported my interpretations of defining the patterns in a participant’s story plot and shaping its structure.

After completing the first level of coding, I started doing the second level of coding. Here, the coding was based on my interpretations and the context of the data. The goal of this step of the analysis was to support the first level of coding and to get a clearer picture of the prostate cancer experiences among the participants. Figure 6 is an example of how the second level of coding was shown in the same excerpts presented in the first level of coding.

The last step in this stage of analysis was to find the themes presented in the participants’ prostate cancer stories.

## The first level of coding

Red colour reflects **Biographical disruption** - Blue colour reflects **cop**ing -Green colour reflects **strategy** – Yellow colour reflects **liminality** – Dark yellow colour reflects **resolution**

### An example on part of narrative about radiotherapy experience:

#### Participant 7's excerpt:

((Sigh)) I had to change my underwear before each prayer. It was because I unconsciously leaked from back and front [urine and bowels]. So, I started wearing two trousers. If one got dirt, I would take a shower and put it in a rubbish bag... Now, I control on my bowels but not my urine. I can't hold it for long... I have limited my visits. If I want to visit my brother, for example, I'll keep asking for the toilet 4-5 times in an hour. The same thing is when I'm in a meeting with men... I'm 70 years old. I frequently use the toilet while I'm sitting with other old men. It's painful. I feel I'm gradually worn down.

#### Participant 9's excerpt:

Sometimes, I couldn't hold myself. I wasn't the only one. I and others were running to the toilet. That period was annoying. There was urine leakage. There was no control. I used to put a tissue to protect my underwear and to keep me pure [clean]. Otherwise, I had to change my underwear every hour. I took medications to regulate and to control urine. Now, I can control it. There is no leakage at all.

#### Participant 13's excerpt:

I had to go to toilet to empty the bladder and then I drank to fill it again. I still feel burning when I pee. Sometimes, I feel a [urine] leakage. I occasionally find a drop. It hasn't affected me much. I change my underwear and then I do ablution.

#### Participant 15's excerpt:

Why I was like that? I mean losing control on my urine and bowel. It was annoying. One day, I lost control on my bowels while I was in a restaurant. I left the restaurant. It was very annoying and disgusting experience. Now, I can control on my bowels but not on urine. Sometimes, I can't hold it while I am going to the toilet... A loss of control [incontinence] may happen and it still annoys me.

Figure 5: An example of the first level of coding

## The second level of coding

### An example of the same participants' excerpts mentioned in level one of coding:

| Direct quotes  | Code   | Category  | A possible theme                                 |
|--|--|---|--|
| I had to change my underwear before each prayer (P7)   | Impacts of urine incontinence or dribbling on religious purity and performing prayer | Disruptive effects and challenges on the religious aspect of life | The radiotherapy treatment disruptive experience |
| I used to put a tissue to protect my underwear and to keep me pure [clean]. Otherwise, I had to change my underwear every hour. (P9)   |  |   |  |
| I occasionally find a drop. I change my underwear and then I do ablution. (P13)  |  |   |  |
| I'm 70 years old. I frequently use the toilet while I'm sitting with other old men. It's <u>painful</u> . I feel I'm gradually worn down. (P7)                                     | Psychological impacts from urinary problems (embarrassment,                          | Disruptive effects on the psychological aspect of life            |  |
| That period was annoying. There was urine leakage. There was no control. (P9)  | annoyed, sense of self)  |   |  |
| <u>Why I was like that?</u> I mean losing control on my urine and bowel. It was annoying... A loss of control [incontinence] may happen and it still annoys me. (P15)              |  |   |  |
| I have limited my visits. If I want to visit my brother, for example, I'll keep asking for the toilet 4-5 times in an hour. The same thing is when I'm in a meeting with men. (P7) | Social impacts from urinary/bowels problems  | Disruptive effects on the social aspect of life                   |  |
| One day, I lost control on my bowels while I was in a restaurant. I left the restaurant. It was very annoying and disgusting experience. (P15)                                     |  |   |  |

**Figure 6: An example of the second level of coding**

### 3.3.6.3 Stage three: applying Bamberg's positioning model on the prostate cancer story

In this stage, the focus of the analysis was on how the participants told their stories. Hence, the analysis process continued with the performance analysis approach, particularly Bamberg's positioning model. Three main questions were developed to analyse the three levels of positioning according to the model of Bamberg and Georgakopoulou (2008):

1. How did the participant position himself in the story?
2. How did he position himself to others, including me, as I was his audience? And how did the other characters position him in the story?
3. How did he position himself with the dominant discourses (master narratives) that were raised in his story?

To answer the first question (the first level of positioning), I looked at the participant and prostate cancer as the main characters of the story (protagonist and antagonist). Then, I examined how the participant positioned prostate cancer, to find how he positioned himself in the story. So, I went back to stages one and two of the analysis and searched for how the participant looked at prostate cancer in the story. I also went through the participant's responses to his diagnosis and treatment, and how he looked at himself currently. This guided me to identify the participant's position in the story.

The second question had two parts (the second level of positioning). The first part was how the participant positioned other characters and how the other characters positioned him in the story. The second part was how the participant positions me as his audience. In the first part, the other characters in the participant's story were mainly his wife, family, health staff including his doctor, relatives, friends, other cancer patients, and people in the community. So, I went back to each story and looked at what the relation was between the participant and each character. The positioning was determined based on how the participant talked about the other characters and their roles in his story. At the same time, I examined how the other characters positioned him through his story, which can be found in how they looked at him since he had prostate cancer. For instance, how the participant's family looked at their father after he got prostate cancer. The changes in the participant's positions might indicate how his prostate cancer experience affected his gender (identity).

In the second part of the second question, I went back through each interview and looked at how the participant included me while he was narrating his story. I searched for the word 'you' in the interview transcription, such as 'You know..., you feel..., imagine you...'. Fludernik

(1994) points out that using the second-person pronoun 'you' in the narrative can be an act of narration. At the same, Fludernik adds that the pronoun 'you' can sometimes refer to the protagonist of the story where the narrator often wants the narratee(s) to share the protagonist's experiences and to participate in the events recounted in the story. In the case of the participants, they as the narrators and the protagonists of their cancer stories possibly used the pronoun 'you' to refer to me or indirectly to themselves. At this point, I found the participants positioned me differently based on the context. For instance, some of the participants positioned me as themselves as a way of explaining their experience, such as filling their bladders before having their radiation sessions. I was also positioned as a Muslim when they talked about Islamic beliefs, such as destiny, when they talked about their diagnosis experiences, or when they talked about the impact of incontinence on performing prayers. Some positioned me as a Jordanian when they talked about cultural values or as a man when they talked about sexuality. Finally, some positioned me as a researcher or a health professional when they talked about medical issues. Apart from the analysis, this step of the analysis was important in terms of the reflexivity of this research. It examined my voice, my influence on the interviews and the analysis process (see reflexivity in the research trustworthiness subsection).

The last question in the positioning model (the third level of positioning) was about how the participants positioned themselves with the dominant discourses, especially the discourse related to masculinity, that was raised in their stories. So, I began by identifying these discourses through the content and context of each story. I discussed these discourses with my Jordanian colleague in the School of Linguistics at Victoria University of Wellington to make sure that the discourses were relevant to Jordanian Islamic culture. Then, I examined how the participant saw himself under these discourses. Based on that, the participant would indicate how his masculinity (identity as a man) was or was not affected by prostate cancer.

Finally, I examined the commonalities between the participants in the three levels of positioning. Then, I integrated the findings from this stage of analysis with Connell's model of the structure of gender relations, discussed in section three in Chapter 2.

### **3.3.7 Presenting the findings**

The findings in narrative research can be presented in two ways according to Holloway and Freshwater (2007). The first way is the traditional one, which is by providing a straight description of the findings, and relevant quotes from the participants. The second way is

through discussing the major findings and linking them to the relevant existing literature. In both ways, the participants' quotes are needed to support the researcher's statements and interpretations (Holloway & Freshwater, 2007).

In this study, I presented the findings in both ways. I did the traditional way in the findings Chapter 4 and Chapter 5, while the second way was completed and explained in Chapter 6. The participants' quotes in the chapters were presented in English. The quotes were checked by my supervisors. I put some of the comments between square brackets in the translated quotes, to help the English reader in understanding the meaning. I also kept paralinguistic features in some quotes to give the reader a better picture of how the participant narrated it.

The findings from the analysis of stage one are presented in Chapter 4. I present in this chapter the typologies of the prostate cancer story narrated by the participants. Under each typology, I explain the parts of the story in terms of the beginning, middle, and end. I support each typology with the participants' quotes in each story, and with some findings of stage two of the analysis to present the commonalities and differences between the participants' experiences. The study's theoretical concepts (biographical disruption, liminality, coping, strategy, and resolution) were already integrated within the presentation of the findings to give a better understanding of the experience. In this way, the chapter gives the reader an overview of the participants' prostate cancer experiences.

The findings from stage two of the analysis are presented in Chapter 5, which is considered as an extension of Chapter 4. In this chapter, the main themes that emerged from the thematic analysis give the reader a better look inside the participants' prostate cancer stories. The integration of the study's theoretical concepts with the findings is also presented in each theme, to support my interpretations and to give a clearer picture of the prostate cancer experience among the participants.

The findings from stage three of the analysis are presented in Chapter 6. In this chapter, I present the findings and discuss them with the relevant literature. The discussion includes the integration of these findings with Connell's model of the structure of gender relations. This, I believe, reinforces my interpretations.

The analysis revealed no outliers (a participant who does not fit neatly within the study's findings). Meaning there were no participants that stated or experienced anything new or distinctly different from other participants' illness experiences. Even the participant who was

not a practising Muslim, had the same kinds of responses to the illness experience as other participants. Therefore, the presented findings reflect the similarity of the data from the participants in terms of their responses and experiences.

### **3.3.8 Maintaining the research trustworthiness**

In this subsection, I describe how the research trustworthiness was maintained in this study. I explain this through reflexivity, subjectivity, rigour and validity, and transferability of the results.

#### *3.3.8.1 Reflexivity*

Reflexivity is an important term in establishing the trustworthiness of narrative studies (Holloway & Freshwater, 2007). It examines each step in the research process, starting from theoretical assumptions, choosing participants, data collection, and analysing the data (Esin, 2011). It also reflects the researcher's background, interests, his/her relationship with the participants, and how these influenced the research process and procedures (Holloway & Freshwater, 2007). Robertson (2006) adds the importance of addressing the influence of masculinity in the reflexive account, especially in research with men. In the case of this study, it is important to present and reflect my own background, research interests and even the influence of my gender on the research process and procedures.

I established my reflective account with how I ended up doing this study. As mentioned in Chapter 1, my personal interests, nursing experience, my master's degree, and the gap of knowledge about this cancer experience among Muslim men were the primary motivations to do a PhD thesis on this topic. But my subjective positions as a Muslim and as a man could also have an influence on my doing a PhD and particularly about this project. I understand Islam as compelling me to seek knowledge and do righteous deeds. This comes from the interpretations of Quranic verses, such as 20:114: "My Lord, increase me in knowledge"<sup>6</sup>, 58:11: "Allah will raise those who have believed among you and those who were given knowledge, by degrees"<sup>6</sup>, and 18:30: "Indeed, those who have believed and done righteous deeds- indeed, We will not allow to be lost the reward of any who did well deeds"<sup>6</sup>. From these verses, I understand that I am requested as a (practising) Muslim to seek knowledge and to do good deeds, such as helping my brothers and sisters in Islam whenever they are in need. Thus, I could meet these requests by completing my thesis about prostate cancer experiences among Jordanian Muslim men. As

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<sup>6</sup> Saheeh International. (2012). *The Qur'an: English meanings and notes* Jeddah, Kingdom of Saudi Arabia Al-Muntada Al-Islami Trust.

I would gain more knowledge from doing this study, the study, and what it adds to the medical literature, would eventually help these men.

In respects to my subjective position as a man – my masculinity could have a hidden influence on doing a PhD that I was not aware of until I started reading about the works of Connell (2000, 2002, 2005) on masculinities and other studies on some forms of Arabic and Islamic masculinities. M. Y. Saleh et al. (2020) indicate that a nursing career in Jordanian society is commonly considered to be a feminine career, where male nurses may experience a social bias due to Arabic culture stereotypes. Thus, doing this degree would shift my career from caring (a feminine aspect) to academic and would add the ‘Dr’ title to my name. Having a high educational level and the ‘Dr’ title would get me a higher social status in my community, which can represent a form of my Arabic (hegemonic) masculinity. This is common among Arab Middle Eastern men like me according to Inhorn (2012). Here, my masculinity could have forced me to take the academic pathway of my nursing career. My reflection at this point made me aware that my Islamic beliefs and my Arabic masculinity would have an influence on choosing my research project and even later while I was undertaking the project.

Before starting my PhD project, and through my work as a registered nurse in New Zealand, I dealt with many people from different backgrounds, sexual orientations, and faiths, whether they were practising it or not. This made me more aware of the perceptions of others of themselves, of their lives, and even of their experiences with illness. But at the same time, it helped in defining who I am as a practising Jordanian Muslim and heterosexual man.

When I started doing this research project and reading more literature about prostate cancer experiences and masculinity, I unconsciously had pre-assumptions about the impact of this experience on Jordanian Muslim men, and its impacts on their masculinity. Because I considered myself a practising Muslim, I had some assumptions about the impacts of this cancer experience on the religious aspect of these men’s lives. For example, I assumed these men, who are practising Muslims like me, could find it a big problem if they suffer from urinary dribbling or incontinence that causes them difficulty in maintaining purity and performing the five obligatory prayers.

I also had another assumption about these men’s sexuality, i.e., how they would talk about such a sensitive topic in front of a young man like me. As a Jordanian and a Muslim, I share with other Jordanians or Muslims the view that sex is an inappropriate topic to discuss with others (see 2.3.2 subsection in Chapter 2). However, my being a man made it easier for the participants

to discuss their experience with sexual dysfunction, which will be discussed below. But before conducting their interviews, I was still concerned about how they would talk about their sexual dysfunction in front of a young man. The works of Connell (2005) on masculinities could answer why I had this concern. According to Connell, masculinity is constructed and performed within the power relational dimension. One form of masculinity is hegemonic masculinity, which is usually presented by strength and dominance and can subordinate other masculinities if they are not underlining these hegemonic standards (ideologies). Potency and physical strength are signifiers of this form of masculinity in many men around the world, including Jordanians (Al Momani et al., 2017; Alexis & Worsley, 2018; Chambers et al., 2018; Rivas et al., 2016). In this case, I assumed that the participants of my research would feel less masculine (which was true for some participants) in front of people like me when they talked about their experience of impotency or feeling weak. This increased the risk of pre-assumption of what signified the masculinity of these men and how their masculinity would be affected by their experience of prostate cancer.

Since this study was my first big research project, it was a challenge to ignore all my pre-assumptions, the influences of my Islamic belief, and even my masculinity, on conducting and interpreting the participants' stories with prostate cancer. Therefore, I tried my best to be aware of the risk of my assumptions and the influences of my Islamic beliefs and masculinity before conducting the participants' interviews. I tried to avoid making assumptions, and let the interviewees tell their experience. I also kept in my mind that Islamic beliefs, practising Islam, and the forms of masculinity among the participants, could differ from mine. So, my mindset was that I expected to see among the participants different beliefs and ways of being a Jordanian Muslim man.

When I started interviewing, I was also aware of the power positioning and relationships with my participants, not only because it could influence how I was constructing their stories but also because it could influence the constructing and presenting of both my masculinity and theirs. The interview setting was in a private room with only me and the participant present. Before recording the interview, I established rapport with the participant and called him 'my uncle', which is a common way in Jordanian society to show respect to older men. It was not difficult for me to build this relationship and trust with the participants, as we have the same religion, language, gender and culture. Sharing the participants' religion, culture and gender, helped them to be open with me, and to narrate their experiences with prostate cancer. Most of

the participants talked about their sexual dysfunctions and sexual life without any direct question from me. Their openness to discuss this topic dispelled my pre-assumptions about their own sexuality. Their openness would be most likely, either because they understood in the first place that I am a health professional with experience, or because we shared the same gender, religion, and culture. So, clearly, it would be different to open up on this topic if the interviewer was a female, or from a different culture. This became clearer in the interviews of Participant 4 and Participant 6 when they talked about their sexuality and their inability to discuss it with their doctor in the presence of his female assistants.

Apart from the topic of sexual dysfunction, some participants openly talked to me about their history of drinking alcohol before being diagnosed with cancer, which interferes with my own Islamic beliefs. One of them said during his interview that he is not a practising Muslim. During the interviews with these men, I was non-judgmental in my interview approach with them. I did not change my voice tone when I asked them questions. I showed my respect for and understanding of their own Islamic beliefs and practices. Moreover, these two men alerted me to the influence of my Islamic beliefs and my own position as a practising Muslim, not only during the interviewing period but also in the analysis process. Here, I had to review again the interviews of these two men to see if my position as a practising Muslim influenced the way I asked the interview questions. As a result, it made me hold back my own views as a Muslim during the interviews with others and recognise their Islamic beliefs and practices. My supervisors, as non-Muslims, also had a significant role at this point, to ensure my non-judgmental analysis and presentations of all the participants' stories.

In terms of power positioning during interviewing, my position as a researcher and nursing professional might have created a form of power imbalance, which as a result could have impacted how the participants constructed their stories and how they portrayed themselves (see the subjectivity subsection below). So, I tried from the beginning to put the participant in a more powerful position by calling him 'my uncle' before, during and after the interview. I also tried to keep them in that power position by being an active listener, and through my interviewing technique (see 3.2.4 subsection in this chapter). This resulted in openness from the participants as they presented their powerful stories and raised issues that were beyond my research interest, such as fatherhood and their social roles.

From another angle, positioning during the interviews means exploring the power relations between me and the participants. In this type of relation dimension, masculinity is constructed

and performed, as noted earlier in Connell's works on gender. Hence, my masculinity and the participant's masculinity were perhaps constructed and performed unconsciously or consciously during the interview. By conducting more interviews related to the prostate cancer experience, my masculinity could be constructed in this context as a young, healthy, able-bodied, and heterosexual Muslim man, which all reflects the heteronormative and hegemonic masculinity. Defining my masculinity in this way helped me to be aware of how my masculinity would impact on theirs during interviewing. At the same time, it helped me later to be cautious in how I saw the participants' masculinity in the analysis process. So, my masculinity as shaped in this way could possibly dominate some of the masculinity of the participants in its aspects of physical strength and sexual potency. In this case, my masculinity could have an influence on the way they constructed and presented their masculinity, while telling their stories. As seen in Chapter 6, some of the participants presented themselves in front of me and to their families that they were still strong even with their illness, as a representation of their (hegemonic) masculinity. But most of the participants, if not all, highlighted other forms of their Arabic and Islamic masculinities, such as being the head of the family, the protector and provider of the house. I do not perform these forms of masculinity because I am a single man. So again, their highlighting these forms of masculinity in front of me possibly indicates that they consciously or unconsciously wanted to represent their masculinity in the presence of me (my masculinity). This all could indirectly have an influence on how they narrated their stories in that way.

During the analysis process, knowing my masculinity and my own Islamic beliefs was important. As mentioned earlier, I was aware of the risk of the influence of my own Islamic beliefs in this research process. So, I tried my best to set my own beliefs aside during the analysis. I tried to find and emphasise what were these men's own Islamic beliefs, and how their beliefs influenced their cancer experience. Similarly, I tried to put my masculinity aside during the analysis, and search for their own type of masculinity. I revisited the transcriptions of the participants' interviews many times to recheck if there was any possibility of finding different types of interpretations of the participants' stories. My supervisors also reviewed all my interpretations from their non-Islamic and non-Arabic perspectives, to recheck whether my interpretations were biased by my own Islamic beliefs or masculinity.

Finally, positioning was also a part of the analysis process of this study. Reflecting on my position was obvious in the analytical process in stage three of the analysis, i.e., how the

participants positioned me in their stories. I discussed in that stage of analysis how they positioned me as a Jordanian, a Muslim, a man, a nurse researcher, and even as themselves, based on the context of their talk. This, of course, maintained my self-awareness in the analysis and interpretation.

In all, my reflexive account made me aware of the influences of my background, my Islamic beliefs, myself and my subjective positions, especially as a (practising) Muslim and as a man. It also showed me how I was an insider and outsider at the same time during the research process. I was an insider in this research not because I did this study but because I shared with the participants their gender, culture, and religion as I am a Jordanian Muslim man too. This, of course, had an influence on choosing the study's topic, and helping people tell their illness stories, and interpreting them within Arabic and Islamic contexts. I was also an outsider in terms of not experiencing prostate cancer, not being married, being young, and having a cosmopolitan experience of living outside Jordan. This distinguished my own voice from the participants in the narrative. All of this enhanced the research trustworthiness in such areas like the subjectivity and validity of the study, which will be discussed next.

#### *3.3.8.2 Subjectivity*

Subjectivity simply means how the researchers have avoided biases or assumptions that may influence the participants and research work in their study (Holloway & Freshwater, 2007). In this study, I showed my subjectivity in the reflexivity subsection when I explained how being a Jordanian Muslim man had created some assumptions about the experiences of prostate cancer among Muslim men. This, as I expected, would cause bias in my analysis, and interpretation of their stories according to my values and beliefs. To prevent this bias, my supervisors and my Jordanian colleague were part of a peer analysis and checking of my interpretations of the participants' stories.

In addition, subjectivity in narrative research can be also achieved by intersubjectivity, which recognises whether the participants' stories are authentic or not (Holloway & Freshwater, 2007). In intersubjectivity, the researcher tries to reflect the issue of power between him/her and the participants of his/her study. This reflection indicates how the participants have power or control to tell their stories in the way they wish (Holloway & Freshwater, 2007). In this study, I met intersubjectivity through reflecting on my position in the interviews, and while undergoing the analysis process. As mentioned in the reflexivity subsection, I also tried to keep the participants in a power position while they were telling their stories.

### 3.3.8.3 Rigour and validity

Validity in narrative research can be achieved through validation of the researcher's works on participants' stories and how his/her representations of their stories are true (Holloway & Freshwater, 2007). In this study, I considered Riessman's (1993) four measurements to ensure the validity of my work:

1. **Persuasiveness.** This occurs when the researcher shows how his/her interpretations are reasonable and convincing. This can be when the participants' excerpts support theoretical claims, and also when the researcher considers alternative interpretations of the data (Riessman, 1993). Persuasiveness was met in this study in the analysis process. The participants' excerpts were linked with the key concepts from the study's theoretical framework, such as biographical disruption, and coping. I also discussed with a Jordanian colleague my interpretations of the participants' stories, to consider any alternative interpretations.
2. **Correspondence or participant checking.** Here, the researcher can take his/her work back to the participants to check accuracy and authenticity (Riessman, 1993). In this study, I offered the participants the option of having a copy of their interviews or reviewing it. However, none of them accepted this offer. Most of them wanted to tell their stories for the sake of helping others. By doing this, they displayed a kind of selflessness and willingness to use their experiences to help others. Thus, I owed all the participants the duty of representing their stories as faithfully as possible.
3. **Coherence.** The researcher strengthens the validity of his/her works by showing the coherence in the presented data (Riessman, 1993). In this study, the coherence was presented in the participants' stories. I have shown the participants' stories in chronological order through the cancer experience, starting with pre-diagnosis, then the diagnosis and treatment experiences, and ending with their current illness situation.
4. **Pragmatic use (decision trail).** This relates to describing how interpretations are produced, what a researcher does, and how a researcher accomplishes successive transformations (Riessman, 1993). In this study, I endeavoured to present full transparency by explaining each step of developing the research methodology and the research process. Each stage was explained and discussed with my supervisors before starting the next step. Even during the data analysis and interpretation, my supervisors and a Jordanian colleague were peer analysing and checking my interpretations using their experiences and objectivity. This, of course, was useful to check the acceptability of data analysis and the reliability of its results.

#### *3.3.8.4 Transferability of the results*

In narrative research, transferability is a more suitable word to use than generalisability because the number of participants is small (Holloway & Freshwater, 2007). However, a model of generalisability is applicable to this study which is processual generalisability. Processual generalisability “shows that social processes are generalisable beyond the specific setting to a variety of other situations” (Holloway & Freshwater, 2007, p. 114). In patients’ stories as an example, suffering from illness or efforts to recover are examples of social and psychological processes that can be generalised to an extent (Holloway & Freshwater, 2007). In this study, I was looking for how Jordanian Muslim men would adapt to prostate cancer. Thus, their adaptation as a process could be generalised up to a point.

### **3.4 Conclusion**

This chapter has discussed in detail the methodology and research process for this study. It presents in its first section the steps of developing the research design, and how this design is strengthened by the study’s theoretical framework. This work acts as a guide on how to conduct the research to meet its objectives and answer its research questions. The chapter continues in section two by presenting how the research was conducted. It describes the process from the step of choosing the research setting to finally how the study maintained the research trustworthiness.

This chapter is clearly explained and is fully transparent in each step of developing the research design and its process. Each step was discussed with my supervisors or with other colleagues to make sure that the whole research process was done in the correct way. This, of course, is very important for the validity of this study and its findings.

# CHAPTER 4: TYPOLOGIES OF PARTICIPANTS’ PROSTATE CANCER STORIES

## 4.1 Introduction

This chapter starts with a table that shows the profile of the participants in this study. Table 1 contains brief demographical information about each participant, such as his age, marital situation, work, and treatment status.

The chapter then gives an overview of the participants’ prostate cancer experiences. It has numerous findings that will be explored and developed in later chapters, including family involvement and masculinity. The findings of this chapter are the outcomes of the holistic form analysis supported by findings from the thematic analysis. The findings are presented through two main typologies (or general responses) which emerged from the participants’ cancer stories. I am labelling the first typology ‘prostate cancer is not the worst kind’. The group of the participants who reflected this typology in their narratives were not overtly worried about pre-diagnosis symptoms or from being diagnosed with cancer. They maintained that cancer itself had not affected their lives. Although some of them still had treatment complications, they chose to adapt to these complications and to practice their life as normal. Essentially, their stories revealed more about adaptation, and to lesser extent forms of resolution. I have labelled the second typology ‘prostate cancer. This is serious!’. The participants who revealed this narrative had been severely affected by their cancer experience, even before diagnosis. Unlike the participants in the first typology, the impact of the difficulties and disruptive experiences were obvious on their lives and through their experience of prostate cancer. This impact was still present at the time of interview. Most of these men were unable to adapt to the complications of their cancer experience and still had the fear of cancer recurrence. Their stories show an obvious biographical disruption, generally ending in liminality.

Each typology has a typical form and I have chosen two participants’ prostate cancer stories to represent each typical form. The chosen stories are presented in the introduction of each typology. Then, each typical form of a typology is explained in detail through three subsections to represent the trajectory (in terms of beginning, middle, and end) of the prostate cancer story. This approach allows me to show the storyline that may be generally reviewed, and to present the similarities and differences between stories within each typology.

### 4.1.1 Profile of participants

**Table 1: Profile of participants and their demographical information and treatment status**

| Participant | Age | Marital status | Work status | Treatment status at the time of the interview | Special notes                           |
|-------------|-----|----------------|-------------|---|---|
| P1          | 78  | Married        | Retired     | Still on HT*                                  | -----                                   |
| P2          | 69  | Married        | Retired     | Completed                                     | Infertile                               |
| P3          | 78  | Married        | Retired     | Completed                                     | Diagnosed with blood disorder           |
| P4          | 60  | Married        | Working     | Still on HT*                                  | -----                                   |
| P5          | 62  | Married        | Retired     | Completed                                     | Has claustrophobia                      |
| P6          | 64  | Married        | Retired     | Still on HT*                                  | -----                                   |
| P7          | 68  | Married        | Retired     | Completed                                     | PSA" level went up again                |
| P8          | 73  | Married        | Retired     | Still on HT*                                  | -----                                   |
| P9          | 75  | Married        | Retired     | Still on HT*                                  | -----                                   |
| P10         | 75  | Married        | Retired     | Completed                                     | Has a medical background                |
| P11         | 68  | Married        | Retired     | Completed                                     | Has a medical background                |
| P12         | 73  | Married        | Retired     | Still on HT*                                  | Had lymphoma                            |
| P13         | 73  | Married        | Retired     | Still on HT*                                  | Has a family history of prostate cancer |
| P14         | 70  | Married        | Working     | Completed                                     | Had colon cancer                        |
| P15         | 70  | Married        | Retired     | Completed                                     | Had laryngeal cancer.                   |

\*HT: Hormonal therapy, which is hormonal injections given every 3 months for 1-2 year on average. "PSA: Prostate specific antigen.

## 4.2 First typology: prostate cancer is not the worst kind

In this typology, the structure of the overall story plot has the ‘regressive, progressive, and then stable patterns’, which resembles the letter ‘V’ (Figure 7). The illness story begins with a slight regressive pattern where the individual describes experiencing unusual symptoms, which pushes each participant to see a specialist. The regressive pattern continues as a growing tension and gradually rises with disruptive physical symptoms continuing to develop after diagnosis, mainly during the cancer treatment period. The storyline then reaches what may be

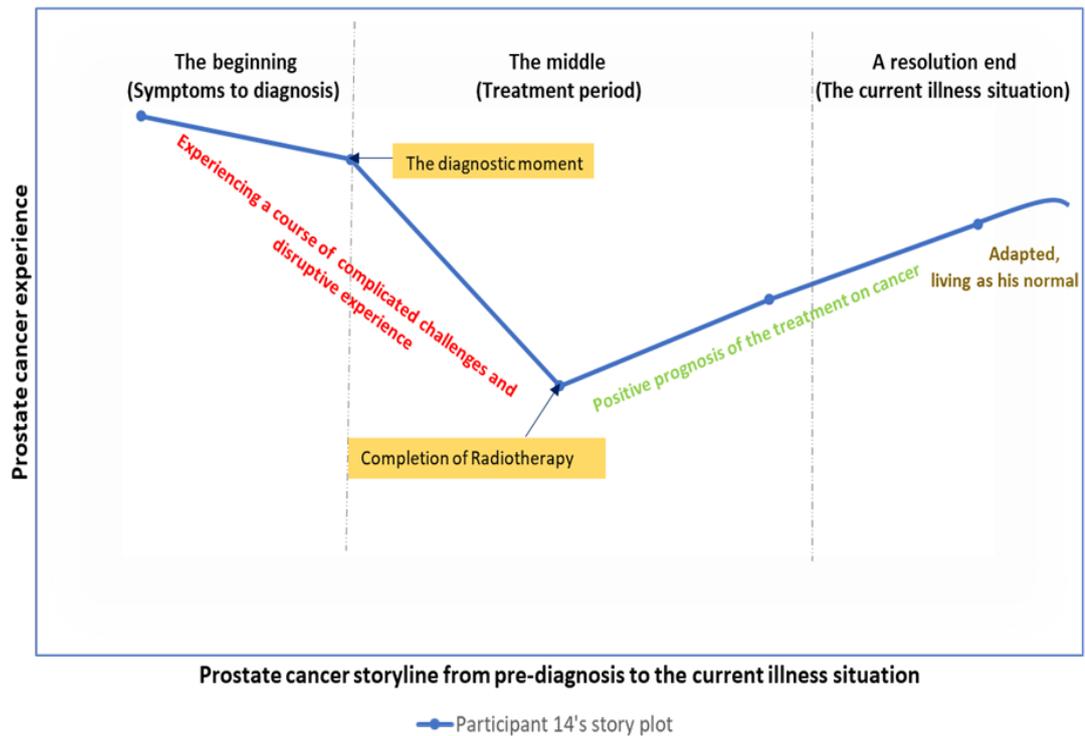
described as a type of turning point which was commonly experienced at the time of completing treatment such as radiotherapy. After this stage, the participants' stories that reflected this typology mainly progress along with the positive recovery such as declining complications of the treatment. Finally, these participants reach a kind of stability, returning as much as possible to their normal life. This stability is the resolution of their illness story.

A typical form of this typology presents in the prostate cancer story of Participant 14. He was a 70-year-old man, who was first diagnosed and treated for colon cancer. His story began with urinary problems, he was not concerned about them until a nurse in one of his follow-up appointments asked him if he had any health problems:

There were urine problems, like a burning sensation. The urine [urinary stream] was not continuous. I tolerated [its discomfort or its physical bothering]. In one of my follow-up appointments for colon cancer, a nurse asked me if I had any problems. I told her about my urine problems. They [a medical team] suspected something. It was prostate cancer. I did not make it a big deal. I was not afraid. I mean I am 70 ((laughing))<sup>7</sup>. It is normal to die at this age or around it. I did not hide the news [of his diagnosis] from anyone. My family's reaction was not bad when they knew. I kept my spirit high in front of them. So, their reaction was based on mine...After the diagnosis, my doctor put me on radiotherapy and hormonal injections. I was massively annoyed by radiation [procedure]. My bladder had to be full. It [having a full bladder] *was really, really annoying*<sup>7</sup>. It was hard and not easy...I peed on myself two or three times while I was in [the] radiation [sessions]. It was not supposed to happen to me...Although this [radiotherapy] period was annoying and tiring, I used to go [to] work after each session...After the radiation [completing the radiotherapy], there was no erection or sexual desire. It was like that for two years. I was okay with that and my wife accepted the situation [his sexual dysfunction]. After I had finished the [hormonal] treatment, my erection and sexual desire were gradually back to normal. Now, I perform [sex] normally, once or twice a week. Everything is back to normal. I mean I work and practice my life as normal. I still travel a lot overseas. Nothing has changed. (Participant 14)

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<sup>7</sup> (( )) indicates non-verbal activity or body gesture. *Italic* indicates speaker emphasis. See Appendix 8.



**Figure 7: Participant 14's story plot**

From the story and Figure 7, it is clear that experiencing pre-diagnosis symptoms accurately illustrated where the participant's story started. He indicated that he had urinary problems but did not take them seriously. This is illustrated in the figure as a slight regression line. The story continued with the diagnosis moment, which is the first turning point in the figure. The participant did not initially perceive prostate cancer as a big problem, even though the diagnosis was the beginning of experiencing challenges and disruptive effects on his life. The participant mentioned a range of physical, and psychosocial challenges he faced during his treatment, such as filling his bladder before each radiation session. More tensions were built up from the side effects of the treatment, such as sexual dysfunction. This is reflected in the figure as a regression line. So, the storyline continued along with the regression pattern until it reached another turning point. In the participant's case, he felt things improved after completing his radiotherapy, and thus a more positive response to the treatment of cancer began to appear. The major indication of this prognosis was having a low Prostate-Specific Antigen (PSA) level, besides the reassurance from his oncologist. Positive prognosis continued with the hormonal therapy as PSA levels remained low. In the figure, this more positive prognosis shows as a progressive line. As time went on, the severity of the treatment's side effects declined, and the

participant returned to activities in his life as normal, or as near normal as possible. So, the progressive line in the figure became a stable parallel line. This was the end of his story that represented the resolution aspect of his illness.

Nine of the 15 participants recounted events that were similar to this typology of the cancer story. Their story plots were comparable to Participant 14's story plot, except for the end of Participant 15's story plot (which will be explained later). More details concerning the similarities and differences amongst the participants' stories in this typology group are discussed in the next three subsections.

#### **4.2.1 The beginning of the cancer story: a slight regressive pattern**

In this stage of the cancer story, the plot began with a slight regressive pattern due to the experience with pre-diagnosis symptoms and the reaction towards the diagnosis with cancer. Nine of the participants, including Participant 14, had similarities in terms of the experience of symptoms, and reactions to these symptoms and their diagnosis with cancer. As in Participant 14's story, most of the participants in this group started their cancer story with the experience of urinary problems, such as weak urine flow, burning sensation, and urine urgency. Participants 10 and 13 are good examples:

Three or four years ago, I started having problems with my urine. The urine [stream] was intermittent. Sometimes, there was burning [sensation]...when it started getting worse, I decided to see a urologist. (Participant 13)

Of course, it started with symptoms of [prostatic] hypertrophy. Urine flow was weak, below the normal...I took capsules that were extracted from pumpkin's seeds. It relieved me a bit, but then it did not work well...Honestly, I did not care, but my sons were worried: "*Oh, papa. Oh, papa*". So, I went to see a specialist. (Participant 10)

It was slightly different for Participant 8. He did not only have urinary problems like others but also sexual problems that caused him pain in his back and pelvis. He thought all these symptoms were side effects of his hernia surgery two years ago. When the symptoms got worse, he decided to see a specialist:

It [the urine stream] was intermittent. I thought it was from the hernia operation. Then, I started having pain from my pelvis to my back...When I was having intercourse, the ejaculation was hard and painful. I hated having sex because of that pain...The pain in my back and pelvis increased, which made me see a urologist. (Participant 8)

The similarity among the participants above, including Participant 14, was not only experiencing symptoms before diagnosis, but also not taking them seriously or living with them until they became worse. This indicates that those participants initially coped with these symptoms. However, aggravating symptoms alerted and convinced the participants to act and

seek medical help. So, they eventually went to see a specialist, who did more investigations, including prostate cancer diagnostic tests such as a Prostate-Specific Antigen (PSA) blood test.

The pathway of seeing a specialist was different for some of the men in this group, even though they experienced similar urinary symptoms. For instance, Participant 1 went to a specialist after a routine PSA test. He indicated having urinary problems before diagnosis, but he did not see the specialist for that, choosing to ignore them. He only decided to have a PSA test when he applied for an overseas visa to attend his son's wedding and needed a medical check-up beforehand:

In 2015, my son overseas sent me an invitation to his wedding. So, I went to the embassy [of that country]. They asked for a medical check-up to get their visa. I had a complete medical check-up, including the PSA enzyme [blood test]. We [himself and his wife] got the visa before the PSA test result came out. It was delayed. So, I decided to get the result once I came back from the wedding...The enzyme [PSA level] was high. I went to a urologist and he asked me if I had any problems with urine. I said [to him] it was fine. I meant that I tolerated [the discomfort or difficulties] the urine intermittency and the burning sensation. (Participant 1)

From the quotation above, Participant 1, like most of the participants in this group, was not too concerned about his urinary symptoms. He was able to manage the difficulties of these symptoms. But at the same time, like others in this group, he also might want to show his strength and toughness through his ability to tolerate and manage the difficulties from these symptoms, which may reflect his masculinity (see more about masculinity in Chapter 6).

Similarly, Participant 3 went to see a urologist after a routine PSA check. His high PSA level was the beginning of his story and the pathway to see a specialist:

I went to the family doctor for regular check-ups. He asked me to do some labs and blood tests, including the PSA [test]. I did the test and it was 14. He advised me to see a urologist. So, I went to the specialist...The specialist asked me if I had any burning sensation with urine. I said: "No. I only wake up two to three times at night for the toilet. It [nocturia] is normal for elderly men to go toilet [many times at night]". (Participant 3)

The participant indicated that he had nocturia before he was diagnosed with prostate cancer. He thought this urinary problem was common or normal to experience in old age. This is possibly why he was not concerned about this urinary problem or sought to see a specialist. However, his high PSA level was a trigger to his family doctor that there was something wrong with his prostate gland. This was the participant's pathway to the diagnosis of cancer.

On the other hand, Participant 12 did not experience any symptoms like the others in this group. His story started when he got a lump on the left side of his groin. He had a biopsy of that lump,

which confirmed a lymphoma. The specialist, who did the biopsy, advised him to do more diagnostic tests, including a prostatic biopsy:

I got here ((pointing to his left groin)) a soft lump, like the size of a lolly. I went to a specialist. He wanted to take a biopsy for it, but he removed it all instead...He referred me to another doctor, who decided to take a biopsy from the prostate. (Participant 12)

In all, this group of participants was in the end seen by a specialist, who ran diagnostic tests for prostate cancer, such as PSA; many had a prostate biopsy. In fact, most of them revealed that they had a prostate biopsy as a diagnostic test. Apart from Participant 10 and Participant 13, the men in this group did not complain about this procedure:

The biopsy procedure was annoying because they used one needle with one gun [the injector]. If there were three guns, the procedure would be finished within 15 minutes...It took half an hour...It was more annoying than painful. (Participant 10)

The procedure wasn't under general anaesthesia, but I felt a minor pain like a sting. Then, I was fine. They [the medical staff] put a catheter in for 24 hours. There was blood [in the urine]. They removed the catheter when my urine became clear. (Participant 13)

Another common feature between the men in this group was their similar reaction to their diagnostic moment. Most of them revealed their positive reaction to the news with quick acceptance of the illness. In Participant 14's story, his response at that moment was highly representable to other participants' reactions in this group at similar moments. As mentioned in his story, he was not worried or afraid when he heard about his diagnosis of cancer:

I did not make it a big deal...I was not afraid...Praise to Allah. Strong faith manages this situation [having cancer]...Again, I am not young to be afraid. I mean I am 70 ((laughing)). It is normal to die at this age or around it. (Participant 14)

From the quotation, this participant indicated how he was not severely affected by the diagnosis of cancer. First, he indirectly highlighted his strong faith, which helped him to manage and accept his illness. Then, he indirectly linked cancer with death by pointing out his age. On one hand, he perhaps wanted to reflect his belief in fate. He presented himself as an old man who was near death with or without cancer, which made him accepting of the situation, even if it resulted from cancer. On the other hand, he possibly wanted to show his boldness and braveness of facing cancer (death) without fear. This can be just 'bravado'<sup>8</sup> or a representation of a form of Arabic and Islamic masculinity (see Chapter 6).

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<sup>8</sup> Bravado means a bold manner or a show of boldness intended to impress or intimidate (Stevenson & Lindberg, 2011)

Other participants from the same group reacted like Participant 14 when they revealed their diagnosis moments. For instance, Participant 8 and Participant 13, both 73-year-old men, were not overtly concerned or affected by the news of been diagnosed with cancer:

I am a believer. Praise to Allah that cancer did not affect me...I mean that what comes from Allah is always good...Also, I am an old man. I mean I have never been afraid of death. If death is my destiny, let it be. What Allah has written; it will happen [pointing his faith in destiny]. (Participant 8)

I accept it [his diagnosis] from day one. I positively reacted when the doctor told me that I had prostate cancer. Praise to Allah. I mean I am a believer in Allah and destiny. A person will not live more than his time. He cannot live. This is it. So, praise to Allah, the Lord of the worlds [an indication of accepting his illness]. (Participant 13)

Both participants talked candidly about being old and death to reflect the common perception of cancer as death. At the same time, they both presented themselves as believers with faith in Allah, destiny, and death, which had a significant influence to ease their anxiety, to positively react to their diagnosis, and to accept it as their destiny.

A similar reaction of not being worried or concerned about the diagnosis of cancer was evident from some men in the same group, but it was for a different reason. Their reaction was based on their view of prostate cancer as a weak cancer that can be controlled. Participant 10, a 75-year-old man, and Participant 15, a 70-year-old man, are examples of that:

There was no fear. I was not worried or afraid of cancer or death. The cancer was confined in the prostate. I have not heard through my [medical] experience that someone dies from prostate cancer. He dies from it if he neglects it and it metastasizes. It is not scary as long as it is confined...But I am not afraid because I can defeat it. (Participant 10)

I did not care because it [prostate cancer] is the weakest of cancers. That is based on my reading. It can be cured or take years to metastasize...It would take 10-20 years to metastasize. At that time, I will perish ((laughing)). So, it did not affect [me]. (Participant 15)

Both participants perhaps perceived their prostate cancer as a weak cancer compared with other types of cancers. In their perception, prostate cancer can be controlled, not fatal, and it takes time to metastasize when a person may die at this cancer stage, which emphasises again the common linking of cancer with death. This perception was possibly the main reason behind not being worried or afraid when they knew their diagnosis of cancer. At this point, these two participants, similar to others in the same group, showed how their perception of cancer and Islamic belief helped them positively react to their diagnosis and cope with it at that time.

The last similarity amongst these men in this stage of their cancer story was in how they handled the news of their diagnosis in front of their families. Most of them indicated in their stories that their families were very worried and concerned about them due to the diagnosis of cancer. Here, their families became involved and part of their illness experiences. This involvement represented a challenge to these men not only in the diagnosis period but also through their various periods of treatment. It was a challenge because of their cultural/ religious responsibilities and male roles as a father and a husband (see more in Chapter 5 and Chapter 6). As a result, they tried to reduce the emotional impact of their illness on their family through different strategies. For instance, as mentioned in Participant 14's story, he kept his spirits high in front of his family to reassure them that he was not affected by cancer. In turn, his family's reaction to his diagnosis was based on his positive reaction. Another example, Participant 1, indicated that his family was very emotional and worried about him when they heard about his diagnosis with cancer. So, his strategy was giving them emotional support and asking them to be strong through faith in Allah:

My sons, daughters, and wife were crying when they knew that I had cancer. I said to them: "Allah puts faith in us. We should be patient to get his rewards. Why are you trying to lower my spirits?". I mean I gave them support. I reminded them about faith to defeat this disease...I asked them: "tighten my waist to tighten yours" [a common Islamic metaphor for support]. (Participant 1)

Hence, both Participant 1 and Participant 14, besides others in this group, tried to show and convince their families that they were fine with their illness. This can be another reason for these participants to react positively towards their diagnosis of cancer, especially in front of their families. From an Islamic perspective, it seemed that they as fathers, i.e., as 'the head' of their families, wanted to maintain their (masculine) role as protector. Further details about the common and observed perceptions of masculinity within Islamic families will be discussed in Chapter 6.

To summarise this stage of the cancer story, there were some difficulties this group of men experienced. These difficulties included experiencing urinary problems, complications from the diagnostic biopsy, and the diagnosis of cancer. Even with these challenges, these participants maintained overall that they faced it and generally coped with it. This is reflected in their cancer story plot as a slight regressive pattern that was eventually resolved. After the diagnosis, they continued revealing a range of challenges and disruptive experience during their treatment period. This will be discussed in the next stage, the 'middle' of the cancer story.

#### 4.2.2 The middle of the cancer story: from a regressive to a progressive pattern

In this stage of the illness story, the plot was a steeper decline in the regressive pattern, i.e., not just continuing in the same way as the diagnosis period. This was because as these participants were experiencing more challenges and disruptive experiences during their cancer treatment. The challenges began with the radiotherapy procedure. These participants each had approximately 42 radiation sessions each. Each session was between 15-25 minutes daily except weekends. They were required to drink copious amounts of fluid to have a full bladder before each session. They were also requested to hold themselves from urinating until the end of the session. As a result, this procedure had physical and psychosocial impacts on these men. It was obvious in Participant 14's story when he expressed how this procedure was very stressful, annoying, and tiring for him. The same negative experience of the procedure was shared by other participants. Participants 8 and 13 are examples:

It [the procedure] was a *big, big, big problem*. Filling the bladder with water. If there was a delay for any reason, I would wet myself. It would be a mess...It [micturition incidents during radiation session] happened to me twice. I tried to hold myself, *but I could not. I could not...*I asked: "Oh, Allah! when will the radiation be over?". It was Eid [a celebration day] for me when I finished. Because I was tired. It wasted my strength. (Participant 8)

Honestly, when I finished the [radiation] sessions, I said to myself if I had surgery [prostatectomy], it would be easier. Because it was tiring. You know that the bladder has to be full. Sometimes, the schedule of radiation sessions was not all on time. It [the delay] caused a lot of discomfort. Sometimes, I had to go toilet and then drink water again [to fill his bladder]...There was also no resting, *every day*. (Participant 13)

From the quotations above, it was clear that the radiotherapy procedure was a major challenge for several participants. The procedure had a significant physical impact on them by drinking large quantities of water, the discomfort of having a full bladder, and tiredness from repeating the procedure daily without rest. Besides that, it caused psychological distress which resulted from holding a full bladder for a while, or from the micturition incidents during the sessions (see more about this part of the illness experience in the first theme of Chapter 5).

Along with the time of having radiotherapy, the side effects of the radiation started to appear. Most of the men in this group experienced urinary and sexual problems, which led to additional tension besides the challenges during the radiotherapy procedure. In the case of urinary problems, most participants experienced urinary urgency, dribbling, and incontinence. Apart from the psychological impact like distress and annoyance, these urinary problems also had a social impact, at least in some cases. Participant 11, a 68-year-old man, is one of these cases:

I stayed at home through my [radiotherapy] treatment period. I mean I became imprisoned at home. Because I did not want to embarrass myself outside in case of having urine incontinence or urgency. (Participant 11)

The participant strategised his risk of having incontinence incidents in public by limiting his social activities during his radiotherapy period due to fear of embarrassment from having incontinence incidents while being outside.

The urinary problems, especially dribbling and incontinence, also had a religious impact by causing difficulty in maintaining their ritualistic purity and performing prayers. This is made clear by Participant 1: “Sometimes, [a short silent interval] I lose my purity in the last second [before or during performing his prayers]”, Participant 8: “When it [urine incontinence] happened, I had to change my underwear or do ablution again to pray”, and Participant 10: “If there is a drop of urine on my underwear, I change it to pray”.

As noted in Chapter 2, Muslims pray five times a day and they need to be ritually pure to be able to perform these prayers. So, they and their clothes need to be clean from urine or stool stains. Then, they need to do ablution, which is a certain way of washing their hands, arms, face, and feet. Consequently, faced with urinary dribbling or incontinence, it was difficult for these participants to maintain their ritual purity and perform the prayers. Sometimes, they had to change their underwear or do ablution again to perform their obligatory five prayers. Therefore, these side effects were in part a unique challenge, and had a significant disruptive impact on these practising Muslim men.

The pattern of the story plot is so far represented as a regressive pattern, as these participants were still facing challenges and disruptive experiences from their radiotherapy treatment (more details about the radiotherapy experience and its challenges and disruptive impacts will be discussed in Chapter 5 as this chapter is just to give an overview of the experience). However, these participants started to have relief from the treatment tensions once they completed their radiotherapy treatment, and therefore there was a turning point in this groups’ general typology within the story plot. That is, as a more positive prognosis began to appear after radiotherapy, in diagnostic tests, and especially in low PSA levels. The participants received reassurance and good news about this prognosis from their oncologist. At this juncture, most of them felt the tensions and challenges that were presented by the discovery of prostatic cancer and the later radiotherapy treatment started to de-escalate. At this point, the pattern of their illness story’s plot became increasingly more progressive. The pattern continued in this way, even though these men were still experiencing side effects from the radiotherapy, and they had hormonal

therapy to complete. They reflected in their stories their coping and adaptation to the complications of both radiotherapy and hormonal therapy.

This was clear in Participant 14's story when he disclosed his experience with sexual dysfunction, a common side effect from radiotherapy and hormonal therapy. He indicated how he and his wife were 'fine' when he had sexual dysfunction for two years. Like Participant 14, all the participants from the same group indicated that they coped adequately with their sexual dysfunction. Participants 12 and 13 are good examples:

They [the medical team] warned me about the possibility of having this [sexual dysfunction]. I mean I am old and my wife too. I do not care about sexual issues. So, thank Allah, the Lord of worlds [an indication of his acceptance of his sexual situation] ...This [sexual dysfunction] has been nearly for three years. I was and am still okay [with it]. (Participant 12)

Of course, it [the cancer treatment] has affected my sexual relationship. Before [the treatment], there was...[sexual activity] but a little. After, it [the sexual activity] was over. Now, it is not at all...I am adapted to the sexual situation...There is no problem. And you know, I am old. I mean [old] in terms of the sexual condition. (Participant 13)

Both participants were 73 years old and still on hormonal therapy at the time of their interviews. From their statements, they indicated the significant impact of their cancer treatments on their sexual function. At the same time, they highlighted their acceptance to their current sexual situation by presenting themselves as old men, and therefore not too concerned about sexual performance. They apparently wanted to reflect that sex becomes less important with aging or that the dysfunction can be viewed as normal with aging (more about the experience of sexual dysfunction will be presented in Chapter 5).

Apart from sexual dysfunction, other side effects resulting from hormonal therapy were mentioned from some men in this group. One of these side effects was hot flushes, which is the experience of feeling hot and having sweating episodes during day or night. A few were considerably discomforted by this side effect:

When I started having the hormones [hormonal injections], I started having sweating...I felt hot in my chest and back like flushes. It was happening every 2 hours for 10-15 minutes and it disappeared. It then came again every hour and a half. There was discomfort. But now, it happens once every two to three days and for a short period. (Participant 8)

I had hot flushes as a result of the [hormonal] injections I took...It caused discomfort. It was mostly happening at bedtime. It started from my legs to my head. I felt hot, but it did not last long. It caused discomfort for a couple to three minutes. Now, it happens but weak. Sometimes, I do not feel it. (Participant 15)

Both participants pointed out that they regarded hot flushes as a hormonal treatment side effect. They expressed that it was an uncomfortable experience since the sweating and feeling hot happened frequently at different times during day or night. Nevertheless, the episodes of hot flushes reduced with time and became weaker. This indicates the decline of the negative influence of the treatment on their bodies, which is also shown in the story's plot as a progressive pattern.

To summarise this stage of the cancer story, there were major difficulties and disruptive experiences among this group of the participants in the period of radiotherapy treatment. The radiotherapy procedure and its complications had physical, psychosocial, and religious disruptive impacts on these participants' lives. All of that was mainly reflected in the story's plot as a regressive pattern. Overall, after completing the radiotherapy, the challenges and tensions began to decline. At this point, along with the positive prognosis of the cancer treatment, the story's plot was curved to a more progressive pattern. This pattern continued with the storyline as the complications of radiotherapy and hormonal therapy either declined or were adapted by these participants. Here, the end-stage of the cancer story, or the 'resolution stage' began.

#### **4.2.3 The end of 'that'<sup>9</sup> cancer story (resolution/liminality): a stable/ unsteady line**

In this stage of the illness story, the trajectory proceeded progressively to become a more stable line by the end. This stable line in the story's plot indicates the stability of the current illness situation of these participants at the time of their interviews, which reflects a possible resolution of the cancer story. So here, the resolution is mainly represented by adaptation to the current illness situation and living life as normal, or back to the normal life as much as it was before the illness. For instance, in Participant 14's story, the resolution was obvious when he revealed his current illness situation:

After I had finished the [hormonal] treatment, my erection and sexual desire were gradually back to normal. Now, I perform [sex] normally, once or twice a week. Everything is back to normal. I mean I work and practice my life as normal. I still travel a lot overseas. Nothing has changed. (Participant 14)

At the time of his interview, this participant had already finished his cancer treatment. He was on regular check-ups and PSA tests every three-six months. From his statement, the resolution

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<sup>9</sup> I use the word 'that' to indicate that the end of cancer story is based on my interpretations of the current illness situations of these participants at the time of their interviews. Their illness situations can change in the future. So, there is NO actual end of their cancer stories since their stories can also change across the time and place. (See 3.2.3 subsection about experience-centred narrative approach).

of his story is represented in how normally he is practising his life in post-treatment. He highlighted that through his ability to perform sexually and in other daily activities, he perceived himself to be 'normal.'

Like Participant 14, another four men from this group of the participants were already on regular check-ups and showing signs of successful readjustment within the resolution stage. Participant 3 is one of them:

After I had the radiotherapy and [hormonal] injections, the oncologist told me that everything was excellent and no danger. Since that time, I have not thought about it [cancer]. I mean I forgot that I had cancer ((laughing)). (Participant 3)

This participant had finished his cancer treatment and had been in remission for several years. In fact, the resolution of his cancer story was represented in being free of cancer, and believing that he was no longer in any danger, he had basically forgotten about it.

In the case of Participant 10, the resolution of his story was similar to that of Participant 14. He claimed that his life had not been changed significantly, although one aspect was clearly still affected by his illness. Yet, he was still practising his life as normal as possible post-treatment, even with the complications of his cancer treatments. He supported his point by stating that he was still able to perform his usual activities save one:

Nothing has changed in my life. I sleep, eat, go out, visit, and travel well. All my relationships with my family, wife, friends, and relatives are still the same...My life is normal, except [sexual life]. My wife understands the situation that I cannot [perform sex]...But we are adapted and satisfied. (Participant 10)

Subsequently, this participant might be said to have adapted well to his illness and treatment requirements, even if his life is not entirely the same as it was previously. This type of resolution, albeit a partial one, was reflected in the statements of other men in this group, who were still on hormonal therapy at the time of interview. The complications and the side effects of cancer treatments still had an impact on their bodies, but nevertheless these participants appeared to cope and adapt to these impacts. They related that their disease and the effects of treatment did not make any significant changes to their lives as long as they were practising their lives as normally as possible, as in the following examples:

I walk, go out, and practice my life normally. No one believes that I am a [cancer] patient. I drive my car. I go and do Al-fajr [dawn] prayer in the mosque. I mean that my situation is normal...Nothing has changed on my social life. Some people get surprised. How come that I am diagnosed with cancer and I still come and go ((laughing)). (Participant 1)

Till today and for two years during my treatment, I drive my car by myself to the hospital. I have not asked my sons to drive me there...I go and do shopping for groceries. I do it sometimes with my wife. I mean that I am not weak, tired, or sick. No. I can [do things independently] until now. Praise to Allah that I am still okay. (Participant 12)

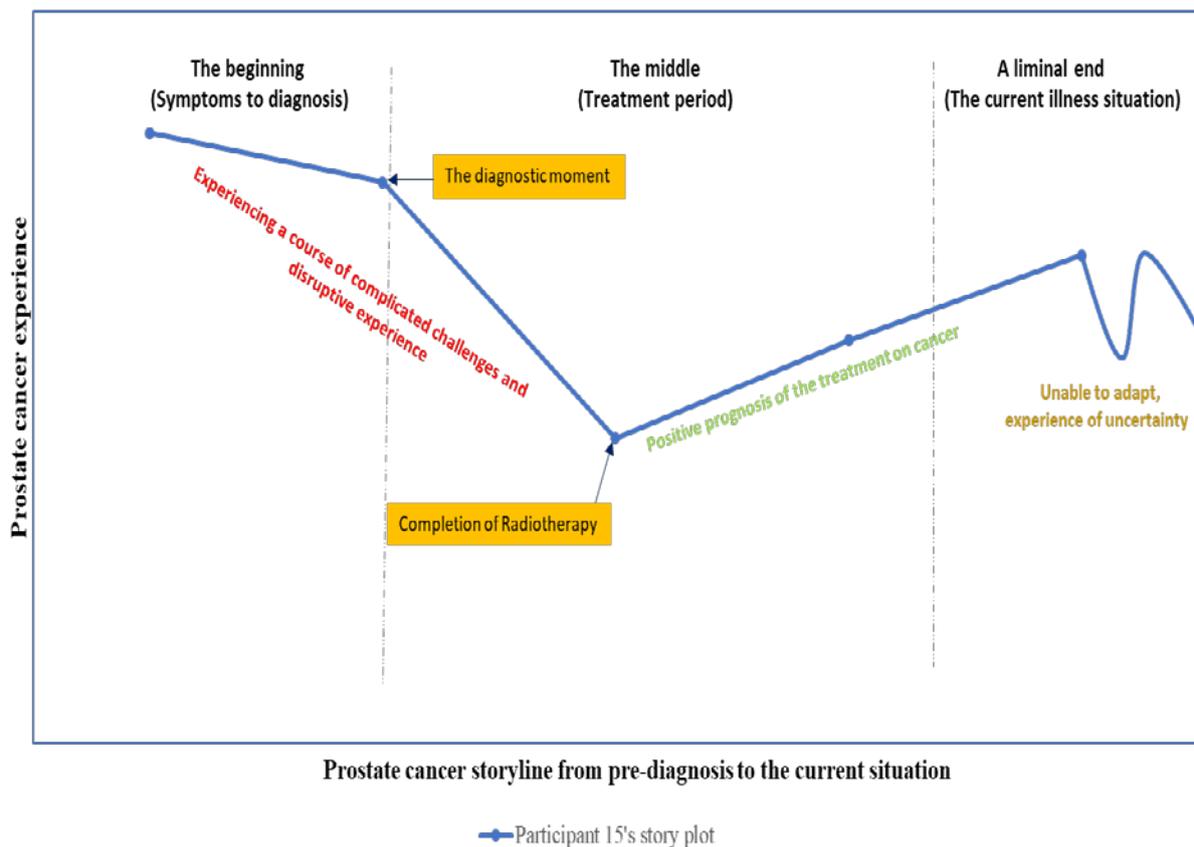
From the quotations above, both participants expressed their current illness situation as one where they are able to carry on with normal activities even though they had suffered from a significant illness and had to face its various treatment difficulties. They indicated that they were currently able to live relatively normal lives, and cancer and its experience had not affected them too much. They supported their point by showing their ability to do ordinary everyday things independently, such as driving, walking, and shopping. This suggests that they had reached a kind of resolution of their illness, which is where their stories end.

In contrast to the above, there was one exception to be found in Participant 15's story when he revealed his current illness situation. He finished his cancer treatment but started having colon ulcers and rectal bleeding with pain only a month before his interview. These post-treatment complications appeared to have resulted from his radiotherapy. Unlike the participants in this group, these complications changed the end of his cancer story to put it in a liminal space (see Figure 8 of Participant 15's story plot below), which represented instability of his current illness as discussed earlier in Chapter 3. The complications had significant disruptive effects on him and his life:

Now and as complications from radiotherapy, I have colon ulcers and continuous bleeding. Whenever there is bleeding, there is pain and it increases with walking. I suffer a lot...I see in myself that I have to work, and I do have the energy to work. But this [illness] situation has stopped me. It is not from cancer itself. No, it is from the radiotherapy complications. It has stopped me from working, even my social activity. I mean my life has become so limited...I *could not walk* because of the severity of the pain...Sometimes, I feel frustration and hopelessness...I am searching for a cure to get rid of it...These complications *truly annoy* me a lot. *It is really troublesome*, especially from the pain when I walk. (Participant 15)

From the quotation and Figure 8 below, the participant clearly showed the physical and psychosocial disruptive effects of his treatment complications, and how these effects still disrupted him and his life. These disruptive effects made his current illness situation unstable and difficult to manage. He was not able to adapt, and uncertain of what to do or what the future will hold. This inability to adapt, and the experience of uncertainty, reflects an obvious disruption and the experience of liminality at the end of his cancer story. Thus, the pattern of his story's plot at this stage changed from a progressive pattern to an unsteady line. However, this participant emphasised in his story that prostate cancer itself did not have any effect on

him, and what was happening to him at the time of the interview were just complications of radiation. Therefore, although clearly different from other participants' stories of this group, I kept his story under this typology of a partially resolved cancer story and categorised it as a subtype.



**Figure 8: Participant 15's story plot**

In summary, this main typology, i.e., of the cancer story has presented the prostate cancer experience for a group of participants. Nine of the 15 participants revealed that they faced through their experiences with prostate cancer a similar range of difficulties and disruptive effects. These difficulties and challenges had considerable physical, psychological, social, and religious impacts on their lives. However, these participants faced, coped with, and used different strategies to manage these impacts. Thus, the biographical disruption and liminality from prostate cancer experience, except for Participant 15's current illness situation, were not obvious in their illness stories. Unlike these participants' cancer stories, the biographical disruption and the experience of liminality were obvious in the illness stories of the other group of the participants. This will be discussed next in the second typology of the cancer story.

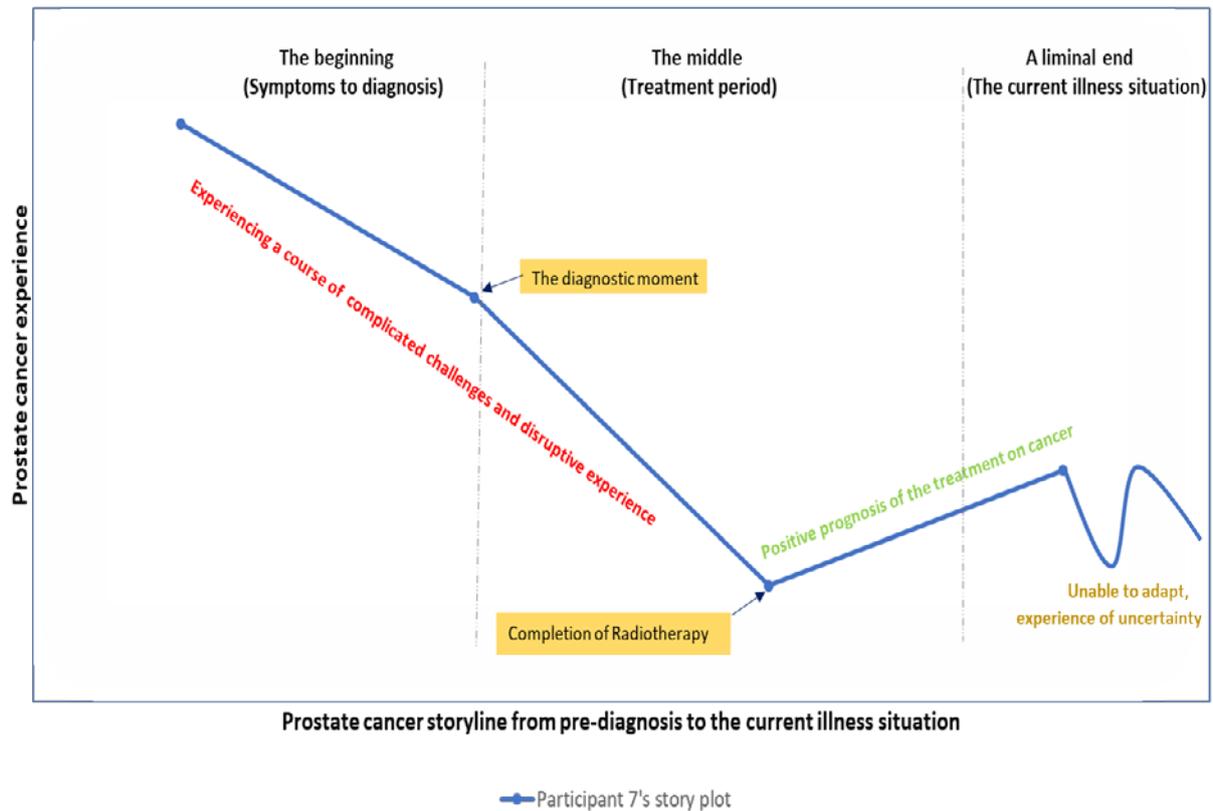
### 4.3 Second typology: prostate cancer. This is serious!

In this typology of the prostate cancer story, the biographical disruption and liminality experiences were more obvious. This typology sees prostate cancer as a terrifying threat. The plot structure for this typology includes a regressive pattern, a slight progressive pattern and unsteady line. The story from the beginning displays a range of difficulties and challenges in the pre-diagnosis period that had a disruptive impact, which reflects as a regressive pattern in the story's plot. Unlike the first typology, the pattern in this typology is regressive right from the diagnosis moment due to feelings of shock, fear, anxiety, and the experience of disorientation and uncertainty, which represents 'acute liminality' according to Little et al. (1998). It remains regressive as more challenges and disruptive experiences are built up during the treatment period. The regressive pattern eventually stops in most cases and curves to a progressive pattern after completing radiotherapy. That is, eventually the tensions and challenges from the discovery of cancer and its treatment started to de-escalate. This is mostly noticeable and occurs about the same time as the positive prognosis of the treatment of cancer. However, this slight progressive pattern stops due to the persistence of the significant disruptive impacts of the treatment complications on men's lives or the return in experiencing uncertainty at their current illness situation. This changes the plot's pattern from progressive to an unsteady line and makes the story end in a liminal aspect.

This typology was found in six of the 15 participants' cancer stories. A typical story of this typology is Participant 7's cancer story and is portrayed in Figure 9. He was a 68-year-old man. He began his story by revealing his urinary problems, which drove him to see a urologist:

I started having difficulty in urinating, going a lot to the toilet, and feeling like a pressure in the lower part of my bladder and testes. I went to a urologist, who ran different tests, scans, etc...The [prostatic] biopsy was painful. There was bleeding [after the biopsy] for 24 hours and then it stopped. After ten days, the results came out...The news was not easy. I felt a kind of grief. Plus, my economic status had an influence. How I would [financially] handle my [cancer] treatment. It had a big role to make me feel sorrowful. I mean I was seriously thinking that this disease would kill me. In seconds, I wished I [would] disappear and never be existed...The house floundered. My family were looking at each other without talking. I reminded them about Allah to settle them down...Of course, I stopped working. I stayed home smoking 3-4 packets a day. Finally, I psychologically accepted the [illness] situation. I mean I did not want to give up. So, I started dealing with the staff [in the radiotherapy department] with joy. They were joyful and accepted me in the same way. *It had a great, great impact on me...*The treatment affected me. I could not hold [the bladder] for long. I peed on myself. It [incontinence] unconsciously happened from back and front [bowels and urine]...I was deprived of my sexual relationship...We used to have sex once or twice a week and suddenly I found myself [a long silent interval] *nothing*...The PSA level

went to normal till 2015 and then it jumped again. The doctor put me again on hormonal injections for another year. The test [PSA level] eventually went to zero. I was happy with the result and unhappy because I did not have the trust in this disease. It may come back any moment...Cancer is not easy. I wish I could defeat it, but I am *weak*...Currently, I feel my [health] situation is not normal. I frequently use the toilet. The difficulty of urinating and its pain are back as before. I doubt that there is something [cancer] in my bladder. (Participant 7)



**Figure 9: Participant 7's story plot**

Figure 9 gives a visual depiction of the participant's story. It shows that challenges and tensions existed even before his diagnosis with cancer, like his negative experience with the biopsy procedure. More challenges appeared with the diagnosis. The shock from the news and handling the situation with his family were not easy on him. Even when he eventually absorbed the shock and accepted his illness, the cancer treatments and its complications created more difficulties and disruptive experiences in his life. Therefore, unlike in the first typology, the regressive pattern in his story plot was a steeper decline from the beginning of the story until he completed his radiotherapy treatment. He continued his cancer treatment with hormonal therapy, which had a positive prognosis on his cancer. His PSA level became low or within a normal range, which again gave some reassurance about this positive prognosis. In the figure,

this prognosis is reflected as a progressive pattern in the plot, as in the first typology. However, this progressive pattern did not proceed for long and changed to an unsteady line. This is because the participant was still suffering from treatment complications. Besides that, he started experiencing urinary problems similar to the symptoms at pre-diagnosis, which made him worried about the recurrence of cancer and experiencing uncertainty at his current illness situation. There was no resolution in his cancer story like the men in the first typology. Hence, unlike the previously described major typology, the obvious disruptive experience from the treatment complications and instability of his current illness situation led his story to end in a liminal space.

This typology has three subsections like the first one, which discusses the stages of the prostate cancer story from pre-diagnosis to the current illness situation (i.e., from the beginning to the end). Through these three subsections, similarities and differences will be revealed not only within the group of (six out of the 15) participants who narrated this typology, but also with the first group of the participants from the first typology.

#### **4.3.1 The beginning of the cancer story: a clear regressive pattern**

In this beginning stage of the cancer story, most participants in this group responded during the interviews in similar ways to the participants in the first group. They began their cancer stories revealing their experience with pre-diagnosis symptoms. These symptoms included difficulty in urinating, urgency, perianal and back pain, and incontinence in some cases. Unlike the first group of the participants, these symptoms were more intense and painful in this group, as described in their stories. Participant 6, a 64-year-old man, is a typical example of this:

I suffered from burning [sensation with urine] and retention [difficulty in urinating]. I felt a burning [sensation] in the urine. When I went to the toilet, I passed a bit [of urine]. Then, I came back again to the toilet. Sometimes, I wetted myself before I reached the toilet. I had to take showers two and three times a day. It was annoying. (Participant 6)

The quotation shows the participant clearly expressed his suffering from the experience with pre-diagnosis symptoms, which he found to be an unpleasant and annoying experience. The combination of the burning sensation, difficulty in passing urine, frequency of having to go to the toilet, and incontinence incidents caused him significant physical and psychological discomfort. In this instance, this reflects the beginning of the regression in his cancer story.

Another example of an intense experience of pre-diagnosis symptoms was evident in Participant 4's story. This 60-year-old man did not suffer from pre-diagnosis symptoms that

related to urinary problems. He mainly complained of severe perianal and back pain after having intercourse:

In a sudden, I started feeling a heaviness into my back when I had intercourse. I ate air [a metaphor of suffering] when I finished the intercourse. I entered the toilet and wanted to *cry* from the pain. I felt it was like an orange pushed to come out from my back. It was not a simple thing...I enjoyed the intercourse but there was no ejaculation ((dusting his hands)) [indicating that nothing comes out with the ejaculation] and I had that pain in my back. (Participant 4)

This participant suffered from dry ejaculation during intercourse, which consequently caused him extreme back pain as he went on to describe. The pain was severe and reached a level that made him cry. This negative experience also represents the beginning of the regressive pattern in his story's plot.

For both Participant 4 and Participant 6, these severe abnormal symptoms required urgent medical help. However, they were unfortunate because they went to many doctors and specialists for the same complaints without an accurate diagnosis or any improvements:

I went to many doctors, not one or two, and without any improvement. Finally, Allah guided me to a specialist, who requested biopsies [from the prostate]. At that time, I did not have health insurance. So, I went to a private hospital and I had the biopsy. (Participant 4)

I went to the doctor. He requested some scans, urine, and blood tests. He prescribed some medications. I did not get better. I was in this situation [suffering from urinary problems] for more than two months and without any benefits...I went to another private doctor. He performed a physical examination and requested some labs and scans. Then, he said: "I want to do a biopsy and it is costly". I said to him: "it is not a problem if it is about [money]". (Participant 6)

From the quotations above, it is apparent that both participants indicated that they suffered from their pre-diagnosis symptoms for a while without a proper diagnosis. This prolonged the disturbing experience from these symptoms, and it possibly caused uncertainty about what was happening to them. Thus, both decided to go to another or a private doctor, who eventually asked them to have a prostatic biopsy. Moreover, they directly and indirectly highlighted that visiting many doctors and having the biopsy in a private health facility cost them more money. This possibly added another challenge (i.e., financial) to their suffering.

The disturbing experience from the pre-diagnosis symptoms was not as significant for other participants in this group, as in the cases of Participant 4 and Participant 6. As noted in Participant 7's story, Participant 6 did not express how bad his experience with urinary problems were. He only indicated that he experienced difficulty in passing urine, which alerted

him to see a specialist. Likewise, Participant 2, a 69-year-old man, only pointed out that he experienced the same urinary problem before visiting a urologist:

When I went toilet to pee, I peed drop by drop. I was in urgency [to urinate] but I could not pee. I just peed a drop by drop. I was like that for a month or less...I went to a doctor in a private hospital. He prescribed two types of medications for two weeks and requested tests. (Participant 2)

In this participant's case as well as in most men in both groups, the presence of symptoms was the trigger for these men and the pathway to visit a specialist. However, Participant 5, a 62-year-old man, was the only man in this group who did not complain of any symptoms. His story was similar to that of Participant 3 in the first typology group who used to attend regular check-ups. This participant began his story when he had a PSA blood test, and the result was a high reading:

One time on a regular check-up, I did a PSA [test] and it was high: 5.4. Of course, I was concerned about it. I visited many specialists in the private health sector. They said that I possibly had an infection in the prostate or urinary tract. They prescribed antibiotics and some other medications...I consulted one of my friends, who is an endocrinologist. He advised me to see a private doctor, who has a specialty in the prostate. I went to this doctor and told him about my PSA high level. He performed an annoying examination [referring to digital rectal examination] ((laughing)). He found hardness [on the surface of the prostate] and he said: "you need to have a biopsy for the prostate". (Participant 5)

Hence, for this participant, the pathway to the diagnosis of cancer was through his regular PSA blood test. He directly expressed that he was concerned about the result as it was high. Like Participant 4 and Participant 6, he went to many doctors, which indicated that he was not confident with their diagnosis or treatment for his high PSA level. So, his many visits to doctors most likely reflected his anxiety and uncertainty about why this test result was high. He eventually went to a prostate specialist, who performed a proper assessment and requested proper diagnostic tests, which revealed that the real reason behind his high PSA level was cancer.

Eventually, all the men in this group went through investigative tests for prostate cancer. One of the common features between these men was their negative experience from those tests, especially the prostatic biopsy procedure. As in Participant 7's story, he experienced pain and bleeding during and after this procedure:

There were more than 18 shots [from the biopsy injector] to take the biopsy. Of course, it was painful because of pulling out meat [the prostatic tissue]. There were no other

side effects, except bleeding. There was bleeding for 24 hours and then it stopped. (Participant 7)

The same negative experience was evident in the story of Participant 5:

Of course, the biopsy was really annoying. I mean it was *terrible*. There was blood after the biopsy...It [the procedure] was *painful* because he [the specialist] took 5-6 samples from a particular or same area. Truly, it was really hard...I tolerated that pain during the procedure. I was severely annoyed. When I went home, a large amount of blood came out [from the rectum]. My feelings became worse. I took Voltaren for the pain and slept. When I woke up the next morning, I felt 80% better. (Participant 5)

The quotations above show the biopsy procedure had physical and psychological impacts on both participants as they suffered severe pain during and after it. Like these two men, Participant 9 was another participant who also suffered from severe pain. This participant described the pain from the biopsy procedure as follows: “the pain after the biopsy was like *death*. It was *very extreme*”, emphasising how severe it was. However, the negative impacts were more significant on Participant 5 because of the bleeding after the procedure. In all, this negative experience in Participants 5’s, 7’s and 9’s stories still represent the continuity of a regressive pattern in their plot.

Another common feature between the men in this group was their similar reactions to their diagnostic moments. Unlike the participants in the first group, these participants were significantly affected when they heard about their diagnosis of cancer. Their feelings were a mixture of shock, fear, anxiety, uncertainty, and depression. An example of this was mentioned earlier in Participant 7’s story when he recalled his diagnostic moment: “The news was not easy. I felt a kind of grief... I mean I was seriously thinking that this disease would kill me”.

Another example of a similar reaction to the diagnostic moment is in Participant 4. He was in shock and terrified when he discovered that he had cancer:

I did not go to get the [biopsy] result but my wife did. She took pictures of the result and sent it to my friend, who is a doctor. He told her that I had cancer. She did not inform me. He called and asked me: “come to my house tonight to smoke shisha”. I went there. He told me straightforward: “listen. This is your story. You have cancer”. Of course, I was shocked at that moment. I swear by Allah that I was terrified. I said to myself: “it is over. My life is over”. (Participant 4)

From the quotation, it was clear that the diagnosis of cancer had a significant psychological impact on this participant. He swore by Allah to declare how shocked and terrified he was of the news. He started thinking that he was near death due to cancer by saying “my life is over”.

His reaction could be related to the common perception that ‘cancer is death’. At the same time, his expression that his life was over also indicates his great uncertainty about his future life.

The same mixed feelings of shock, fear, and terror were dominant for other participants in this group, like Participant 2 and Participant 6. The word ‘cancer’ was enough to make them extremely frightened:

The doctor told me I had prostate cancer. You know what I mean. I mean that I was afraid because it was cancer. *What! Cancer.* I was terrified. Anyone would be afraid. My nerves collapsed [an expression of shock]. I said: “I was over”. (Participant 2)

I swear by Allah I was scared in the beginning. You know that the word ‘cancer’ is scary. A person gets scared and goosebumps of it [cancer]. So, it was *very scary*. Truly, I was terribly tired and in pain. (Participant 6)

Both participants expressed the severity of the psychological impact when they heard the news of their cancer diagnosis. They both stressed that cancer is a scary disease, and anyone would be terrified and afraid if they were in their situation. This, again, suggests the common negative perception of cancer as a scary and deadly disease.

For Participant 5 and Participant 9, their diagnosis with cancer also had a psychological impact, similar to the experience of men from the same group:

I mean it is Allah’s will. I praise Allah in all situations. Even though, I was psychologically upset. There is no human will not be upset when he gets cancer. But again, I am a thankful slave when I say: “praise Allah”. (Participant 5)

Of course, a person would be psychologically [a short silent interval]. This is *an evil disease*. I mean I was psychologically [a short silent interval], even I am a believer in Allah and do prayers since I was young. But again, you would be in a different psychological situation, like *depression*...If a person was not [strong] against this disease, he would lose. You know it is cancer. (Participant 9)

Both participants presented themselves as good practising Muslims through doing prayers, praising Allah in good or bad life situations, and showing their faith in Allah and his will. Presenting themselves in this way was an indication of their attempt with their Islamic faith to ease their distress and anxiety, and to cope and accept their diagnosis with cancer, as was seen in some men in the first group. Despite their faith in Allah and his will, these two men emphasised that being diagnosed still had a significant psychological impact on them because the disease was cancer. This further reflects their negative perception of cancer.

The shared disturbing psychological experience among this group of men in this diagnosis period had a sequential impact in some men. An example of this was mentioned in Participant

7's story when he said: "Of course, I stopped working. I stayed home smoking 3-4 packets a day". Another example is seen in Participant 4's story:

I swear by Allah that I retreated in the beginning. I did not want to see anyone, no one even my brothers and sisters. I stayed at home. I took leave from work. I did not want to talk with anyone. (Participant 4)

Staying at home, not seeing or talking to people, stopping work, and heavy smoking are indicative of both participants' experience of depression during the diagnosis period. Stopping work and isolating at home created other social and possibly financial impacts on them. This also explains more about the disruptive experience and the continuity of the regressive pattern in their story's plot in this stage.

Besides the negative experience among men in this group from their diagnosis, the diagnosis created more tensions and challenges by distressing their families. As mentioned in Participant 7's story, the news of his diagnosis worried his family and left them speechless: "The house floundered. My family were looking at each other without talking. I reminded them about Allah to settle them down". From the quotation, the participant expressed how the news of his diagnosis with cancer caused a significant kind of chaos and shock to everyone in his house. Consequently, he, as the head of the house, tried to calm them down and reduce the shock. His strategy to calm his family down was similar to some men in the first group, by reminding them about the faith in Allah. In this group, Participant 2 shared the same experience and the strategy technique with his wife when she was told about his diagnosis: "Of course, she was terrified and started crying. I asked her to put trust in Allah. What comes from Allah is always good". Participant 2 indicated that his wife was emotionally affected by the news of his cancer diagnosis. Yet even after his shock from the news, he tried to reassure her by reminding her of Islamic faith in Allah's will and destiny.

Some men in this group hiding their cancer diagnosis was a strategy they used to reduce and protect their families from the distress of their illness. Participants 5 and 6 are examples of this, as illustrated in the next two excerpts:

I did not spread the news. Even my sons, they do not know about my diagnosis. My sons are not old enough. The eldest is 25 years old. I am worried about their worries. If they know that their father is sick, they will be too worried and stressed...My son will think about what will happen next to me and how much time is left for me to live. Their feelings will be disturbed. (Participant 5)

I did not tell my youngest son. I told the eldest one. I did not tell my married daughter, but she knew through her husband. I did not want them to know. I did not want them to

get hurt in the first place...Unfortunately, my wife discovered my diagnosis through the stamp of the cancer centre on my medical reports. She was massively affected. I reassured her to increase her spirits...I do not tell my family about my problems. This is my nature. (Participant 6)

From these two and the previous examples in both groups, it was common among these participants to not want to worry or to allow their families to become too involved with their illness. In both groups, the participants used different strategies to protect their families from the impacts of their illness. On one hand, this indicates that the impacts of the cancer experience had consequential effects on the family too. This, of course, tended to build up more tension and difficulties for these men not only in the diagnosis but also throughout their treatment period (see Chapter 5). On the other hand, these participants' behaviours possibly represented an aspect of their Arabic and Islamic masculinities by protecting their families and maintaining this role through their cancer experiences (see Chapter 6).

Unlike the first group, the participants in this group took more time to accept their diagnosis with cancer and develop coping strategies. This was mentioned in Participant 7's story when he stated: "Finally, I psychologically accepted the [illness] situation. I mean I did not want to give up". The participant here indicated that he became more emotionally stable regarding his diagnosis and became ready to move on with his illness. He eventually pulled himself together and wanted to face his illness again by not giving up. All of this represents his gradual coping with his diagnosis of cancer and slowly accepting this new illness situation.

Some men in this group highlighted the influence of support from their families and healthcare providers to accept their illness. Participants 4 and 9 are examples of this:

I was referred to a psychologist. I had two sessions with her...Praise to Allah. My wife consoled and felt for me. She said to me: "Life is not over. Any human is vulnerable [to get sick or get cancer]. He will not live forever. What Allah has written; it happens". I swear by Allah that I have taken her words as a rule. He who has strong faith in Allah, will not be afraid of death or cancer. (Participant 4)

The doctor said to me: "the cancer was still in its beginning. It can be cured. Put trust in Allah. You will recover in Allah's willing"...My wife is a strong believer. She has tightened my waist [an Islamic metaphor of support]. She keeps telling me: "Not to be afraid. This is from our Lord"...I am patient and the patient gets rewards [from Allah]...In the end, I submitted to Allah, the one who cures. (Participant 9)

In both participants' cases, it was obvious that the strong influence of these men's wives and their doctors in reassuring and showing hope to them. Strengthening the men's faith in Allah and destiny was a helpful strategy to assist them to accept and cope with their illness. This was also noted in some men of the first group when they indicated their quick coping and acceptance

of their diagnosis. At this point, it indicates the positive influence of faith in Allah, his will, beliefs of destiny and death, on men to ease the psychological impact of their diagnosis with cancer, and to accept it.

To review this stage of the cancer story, the participants in this group revealed a clear range of difficulties and disruptive experiences, which mainly came either from the pre-diagnosis symptoms, the diagnostic tests, or from the diagnosis with cancer. Unlike the first group, the difficulties and negative experiences were more intense for the men in this group as they recounted in their stories. Thus, the pattern of the plot in this stage was more regressive comparing with the first typology in the same stage. Although the men in this group eventually accepted their diagnosis with cancer, more tensions and challenges were built up throughout the period of the cancer treatment. Hence, the regressive pattern did not stop after their acceptance and continued with the middle stage of the cancer story.

#### **4.3.2 The middle of the cancer story: from a regressive to a slightly progressive pattern**

In this stage of the illness story, the plot remained with a regressive pattern as the participants in this group faced more challenges and disruptive experiences from their cancer treatments. In some ways, they shared a similar negative radiotherapy experience with most of the participants in the first typology group. They had the same issues related to its procedure, such as drinking large amounts of fluids, filling and holding their bladders, and coming to the Cancer Centre daily. These issues caused physical and psychological discomfort for most men in most instances. In this group, Participant 6 and Participant 9 described examples of this:

I took 44 [radiation] sessions. I suffered from drinking much fluids. Sometimes, I wanted to pee while on my way [to the cancer centre]. I had to stop over at cafes or gas stations for a toilet...I could hardly hold myself during the radiation sessions. One-time while I was on the [radiation machine] table, I wet myself and filled the room with urine. I usually could hold on, but I *could not* that time...I *suffered*. I could not believe it when I finished my radiotherapy. (Participant 6)

I used to come every day. I took 42 sessions and each session was 25 minutes each day. I had to drink a litre and a half every day [to fill the bladder]. You need to find a solution to this issue. Sometimes, I could not hold myself. I was not the only one, me, and others. We were *running* to a toilet [after the session]. That period was annoying, very stressful. (Participant 9)

These two men, as well as many participants in both groups, expressed how distressful their radiotherapy treatment was. Having the same issues from the radiotherapy procedure and sharing its negative experience indicates that this period was a major challenge for most participants in this study, as it may be suggested, it might be for most men.

The shared disruptive experience from radiotherapy was also not limited to physical and psychological impacts on the participants' lives. The urinary problems like dribbling and incontinence also created religious challenges for some men in this group. An example in this group is present in Participant 7 and Participant 9:

((sigh)) I had to change my underwear in each prayer. Unconsciously, it [urine] leaked from me. Whenever I go to a toilet, I check my underwear if it is wet. Of course, I wash the lower [body] part or take a shower and change my clothes. (Participant 7)

Whenever there was [urine] dribbling, I put a tissue to keep the underwear clean. This was for purity. I had to do this for purity. Otherwise, I would change my clothes every hour. (Participant 9)

It was obvious that urine dribbling, or incontinence caused difficulty in maintaining the men's ritual purity to perform their prayers. To overcome this difficulty, both participants created strategies to keep themselves clean and maintain purity. For Participant 7, his strategies were by continuing to check his underwear, taking a shower, and changing the underwear. In Participant 9's case, he used a tissue to keep his underwear clean.

The experience of sexual dysfunction was another common side effect from radiotherapy, which worsened with hormonal therapy. This experience was shared among all the participants in both groups. However, unlike the participants in the first typology, the disruptive experience from sexual dysfunction was more present in the stories of this group of the participants, and clearly more persistent. As mentioned in Participant 7's story, he was sexually active before his cancer, but he became totally inactive after it:

We used to have sex once or twice a week and suddenly I found myself [a long silent interval] *nothing*...The most thing that would kill a man is being diagnosed with prostate cancer and being [sexually] away from his wife. A man can bear anything except losing his manhood. It is hard, especially when his wife looks at him. I have been like a rag beside my wife for 6 years. (Participant 7)

From the quotation, the participant showed how significantly his sexual life had been affected for six years. He expressed himself as a 'rag' to indicate how bad his sexual function had become. At the same time, he directly highlighted that losing sexual function was like losing masculinity. This suggests the negative impacts of this experience on his sense of being a man (see Chapter 6).

A similar disruptive experience was also evident in Participant 2 when he revealed his experience with sexual dysfunction:

I used to have sex once or twice a week. I stopped having intercourse once I started taking the hormonal injections with radiotherapy...I had tried many times to sleep with her [an expression of having sex], but it [penis] did not stand up [no erection]...I *despised myself*. I was entirely affected. I wanted to be like any man who has normal sex with his wife. (Participant 2)

This participant as well as others in this group shared the same negative feelings towards themselves in response to their experience with sexual dysfunction. Unlike the first group of participants, most of the participants in this group were psychologically affected. They were not able to adapt to it, where some of them were still emotionally distressed and uncertain about the future of his sexual function. Their negative experience with sexual dysfunction reflects the continuity of the regressive pattern in their story's plot in this stage.

Moreover, the experience of hot flushes was another common side effect that was recounted by the participants in both typologies during their cancer treatment. Compared to the first group, this side effect was more inconvenient to some men in this group and caused some annoyance. An example of this is found through Participant 4 and Participant 6:

Oh, these hot flushes from the [hormonal] injections make me *mad*. My head is always excessively wet [from sweating]...I want to put my head in a freezer. I use a face towel all day to wipe [the excessive sweating]. I asked the doctors and they said no treatment for it. (Participant 4)

The hormones [hormonal therapy] was also annoying. Sweating, hot flushes come 10-11 times day and night, in summer or winter. I do not use tissues. I use a face towel [an indication of the excessive sweating]. Sometimes, I put my head under tap water just to get it cold. The sweating problem *kills* me. [It happens] even in people's houses. I keep wiping [the sweating]. (Participant 6)

From the quotations above, both participants expressed how their experience with hot flushes caused them physical and possibly social discomfort, and just how distressing they found it. This was because of the frequency and intensity of feeling hot and sweaty. Participant 4 pointed out that there was no solution for hot flushes according to his doctors. He and Participant 6 described using a face towel to wipe the excessive sweat and just tolerated the discomfort.

Mindful of the disruptive experiences among this group of participants during their treatment period, it is perhaps worth noting that there was the support provided by the healthcare staff in the Cancer Centre. This aspect of the participants stories will be revisited in later chapters but is offered now as an indication that all of the participants found support from various sources in various ways, and such support made a considerable difference to their confidence in the treatment and their eventual prognosis. For instance, as revealed by Participant 7, he acknowledged this support and how it created a positive atmosphere in such a stressful period:

I started dealing with the staff [in the radiotherapy department] with joy. They were joyful and accepted me in the same way...They treated me well. The doctor treated me humanly [with empathy] before he acted like a doctor. *It had a great, great impact on me.* It was amazing when my doctor came to welcome me while I was waiting for my appointments. He reassured me that my blood tests were fine, even if the PSA level was high. He gave me a kind of self-confidence to pass this [the treatment] phase. (Participant 7)

The participant emphasised the support he received from the healthcare team had a positive psychological influence on him. With all the tensions and challenges, particularly from radiotherapy, the reassurance from his oncologist gave him the confidence that the cancer was under control.

Similarly, Participant 6 declared how the support from the medical staff gave him trust and hope of curing his cancer:

I met a guy [a medical staff] when I started the treatment in this centre. He, many guys, and my doctor increased my spirits...During the treatment, I trusted in their words [the facts were explained to him about prostate cancer and how it could be cured]. I gradually gave trust in the treatment. I seriously trusted them. I gradually became more relaxed. (Participant 6)

For this participant and others in this group, the support and reassurance from the healthcare providers increased their spirits in facing cancer and gave them hope that with treatment that cancer could be cured. Hence, their anxiety and fear of cancer reduced. They indicated in their stories that they felt more comfortable when their oncologists reassured them with a good prognosis of treatment. For most men, including Participant 7, they referred this prognosis to having a low PSA level after completing the radiotherapy. Here then, was the turning point where the regressive pattern of the story plot stopped and curved to a slight progressive pattern (see Figure 9 of Participant 7's story plot on page 89 above).

Similar to the first typology, the progressive pattern in this typology reflected the positive prognosis of treatment on the cancer, adaptation to the treatment complication, or declining in the severity of these complications on men's lives. For some men of this group, the severity of some of the treatment complications had reduced or were responded to via eventual acceptance and adaptation. Participants 2 and 5 are examples of how their sexual dysfunction was adapted or reduced:

There was sexual desire but without an erection. I asked my doctor and he said: "after the radiation and the hormonal injection. You need time". I am actually back to normal after a year...I can have intercourse with my wife but not with a full erection or ejaculation. (Participant 2)

My sexual situation has significantly been affected. My sexual relationship has decreased. The sexual desire is only in my mind...I have accepted it as a reality...I am in my sixties. I am an old man, and this is my limit. I mean I am retired from work and sex ((laughing)). (Participant 5)

For Participant 2, having an erection to normally practice sex with his wife was a recovery for him, even with the presence of other sexual problems such as dry ejaculation. Then again, Participant 5 indicated that his sexual life was significantly affected. But at the same time, he was like most men in the first group, he coped and accepted his altered sexual condition as his new normal. In both participants' cases, adapting to the new sexual condition as normal or the return to normally practice sex demonstrated the progressive pattern in their stories' plot.

The progressive pattern was also presented in Participant 6 and Participant 9 when the severity of their urinary problems lessened along with time and special medications:

I got better. I mean I am not like I was before. I become able to hold [the bladder] for half an hour, two or three hours. Sometimes, I do ablution at Asr [afternoon prayer time] and stay [pure] until Isha [night prayer time]. The urine problem was a real problem. It has reduced a lot. I feel *much better*. (Participant 6)

I used to take medications [for urinary problems]. One was for the burning sensation with urine and the other one was to control urine flow or dribbling. Now, I do not have it [these urinary problems] at all. (Participant 9)

Again, it was obvious in both participants that they reached a degree of recovery from their urinary problems, which before were causing many difficulties in their lives. This kind of recovery was reflected as the progressive pattern in the plot of their illness's stories.

To conclude this stage of the cancer story, there were some similarities and differences between both groups of the participants in the treatment period. Like the participants in the first typology, most of the participants in this typology experienced similar types of difficulties and disruptive experiences from the radiotherapy, especially from the procedure. This suggests the common regressive pattern of the story's plot in this phase in both typologies. Nevertheless, the participants in this typology expressed more disruptive experiences from the significant impacts of the treatment complications on them and their lives. This was clearly noticeable in their quotations that illustrated their experiences with the common treatment complications, such as urinary and sexual problems. Along with time, the positive prognosis of the treatment appeared on their PSA level results. The oncologists' good news and reassurance to these men reduced the anxiety and tension from cancer and its treatment, which caused a curve in the pattern of the illness story's plot to progressive. Like the first typology, the progressive pattern continued with recovery or adapting to the complications of the treatment. However, this slight

progressive pattern did not continue as in the first typology. It shifted to an unsteady line because of the persistence of treatment complications and the recurrence of uncertainty in cancer and its recovery. This will be discussed next.

#### **4.3.3 The end of ‘that’ cancer story (liminality): an unsteady line**

This stage of the illness story presented the current illness situations of the participants in this group at the time of their interviews. Unlike the participants of the first group, their current illness situation was still unstable due to the persistence of the impact of the cancer treatment on their lives and the concern about cancer recurrence. Thus, the progressive pattern of the story’s plot changed to an unsteady line to reflect this instability of their current illness situation. An obvious example of this instability was mentioned earlier in Participant 7’s story:

I was happy with the result and unhappy because I did not have the trust in this disease. It may come back any moment...Cancer is not easy...I wish I could defeat it, but I am *weak*...Currently, I feel my [health] situation is not normal. I frequently use the toilet. The difficulty of urinating and its pain are back as before. I doubt that there is something [cancer] in my bladder. (Participant 7)

From the quotation, the participant clearly stated that he was still suspicious of cancer recurrence by saying “it may come back any moment”. His current experience with the same pre-diagnosis urinary problems made him more suspicious about the recovery from his cancer. At this point, it suggests that the participant was again experiencing the uncertainty and disorientation about his current cancer situation or future life. His current experience represents the experience of liminality (see section four of Chapter 2), which situates the end of his story in a liminal space. This means that we are not sure how the story would really end. It may end with time and reach a kind of resolution like in the first typology or the illness situation gets worse, and the story’s plot continues with a regressive pattern.

Like Participant 7, the fear and anxiety of cancer recurrence were also evident in other men of this group. Participants 2 and 5 are good examples of this:

Last time when I did the [PSA] test, he [the oncologist] said to me: “there was totally nothing [PSA level was nearly zero]. Be assured”. He said that to me twice. I was psychologically relaxed. It was over. It had gone from me. Then, he said to me that I have to recheck every 6 months. I asked him why was for. He said: “because it is malignant”. I cannot rest assured with this disease. It may come back. It actually happened to a man I know...To be true, I have an obsession that I may have it again. (Participant 2)

I noticed in the last two years that the PSA gradually increased. I mean it [PSA level] was 0.15 six months ago. Now, it is 0.2. I always ask the doctor. He [the oncologist] said: “it [the PSA level] is normal [to increase] and we do not go again for [hormonal]

treatment unless it jumps above 2.0"...This disease needs to be treated. It is not easy, and a person is afraid if it metastasizes. (Participant 5)

Both participants above completed their cancer treatment and were on regular check-ups at the time of their interviews. Their quotations show they experienced anxiety and fear of cancer or its recurrence again, even with the reassurance from their oncologists. The experience of anxiety and fear suggests the instability of their emotions and uncertainty about their future with cancer. This, again, reflects the instability of their current illness situation and keeps their illness stories in a liminal space. Their stories may continue with adaptation and end with a resolution or with regression due to more disruptive experiences.

Apart from the anxiety and fear from cancer and its recurrence, some of the participants in this group revealed the significant disruptive experiences at their current situation, which also indicated that the end of their story was in a liminal mode:

Sometimes, I feel that my legs cannot carry me. One-time last March, I fell down while I was walking. I was only carrying a laptop bag. *I did not believe that.* I did not know why my legs did not carry me. *I did know why...* I used to be *very active*. I used to fix by my hands. Now, ((with an angry tone)) I cannot knock a nail. I easily get sweaty and tired. I am always idle. *Has my body weakened to this level?* (Participant 4)

After a month or two from completion of radiotherapy, I started having pain in all this area ((pointing to his pelvis and back)). It is mainly in my back and it goes down to my knees. I suspect there is still cancer because it [the pain] is in the same area...I was an athlete. All of my life, I used to swim, play, and walk for long distances. Now, I cannot walk 500 meters because of the pain. This is not my norm... Until now, I am not back to my normal because of the pain. It is *troublesome*. (Participant 9)

The two participants pointed out the complications of their cancer treatments in their current situation. They declared significant disruption and a transition of themselves due to these complications. The biographical disruption and the transition were obvious when they stated how they declined from being active and healthy men to what they perceived as a much weaker state (see more in the fourth theme in Chapter 5). The persistence of disruptive experiences on them and their lives also reflects the instability of their current illness situation, and arguably leaves them in a state of liminality. This is where their illness stories ended.

In all, the liminal end of this group of the participants' stories was unlike the participants in the first group (except perhaps for the end of Participant 15's story). This end presented their unstable current illness situation, which was due to their fear and anxiety from cancer, the significant impact of the treatment complications on them and their lives, or the inability to adapt to these complications. Yet, this end suggests the possibility at least of continuity for the cancer story towards a possibly good resolution, as in the first typology, or possibly a bad

resolution (regression), or a state somewhere in between. The end can basically depend on the illness situation in the future and how these participants experience it. This point also suggests that the good resolution end in the first typology may not last for long and it can be changed to liminal as in the second typology.

#### **4.4 Conclusion**

Through the main two typologies of the prostate cancer story, this chapter has shown an overview of how prostate cancer experiences among the participants have varied. The first group of the participants quickly accepted their diagnosis with cancer, coped, and used different strategies to face and adapt to these challenges and disruptive impacts. Subsequently, the adaptation and resolution are largely clear in their illness stories, even with the presence of disruptive experiences. On the other hand, biographical disruption and the liminality experience are more obvious in the cancer stories of the second group of the participants. Even with their attempts to face and adapt to their cancer experiences, the challenges and disruptive impacts had significant disruption on themselves and their lives, and most of them were still struggling with this disruption at the time of their interviews.

This chapter has also demonstrated the influence of the perception of cancer and Islamic beliefs on the participants' reactions and acceptance of their illness. Faith in Allah, destiny, and death has a positive influence on most of the participants to accept and positively react to their diagnosis with cancer. On the other hand, linking cancer with death causes some participants fear, anxiety, and uncertainty about their future. This chapter also firmly outlined that healthcare providers and the participants' families were involved in the cancer experiences of the participants. The involvements of these people have both positive and negative influences on the participants' cancer experiences.

The next chapter will reveal considerably more details about the participants' experiences with prostate cancer, especially after the diagnosis.

# CHAPTER 5: THEMES FROM PARTICIPANTS' STORIES

## 5.1 Introduction

The previous chapter presented an overview of the prostate cancer experiences among the participants of this study. It has shown through their stories how their experiences with prostate cancer were filled with difficulties and disruptive impacts that affected the physical, psychological, social, and religious aspects of their lives. It outlined that all the participants were affected in different ways from these difficulties and disruptive impacts but responded differently with it. Therefore, some participants successfully faced and managed these challenges and disruptive impacts, and as a result, were not significantly affected by their cancer experience. On the other hand, it also showed other participants, who were significantly affected by these challenges and disruptive impacts. So, the various forms of disruption and uncertainties from their cancer experience were more obvious in their stories.

This chapter is an extension of the previous chapter, its main aim being to provide a deeper understanding and a clearer explanation of context for the study's findings. To achieve this, the main outcomes of the thematic analysis (stage two of the analysis process) are presented and reframed alongside discussion concerning concepts from the study's theoretical framework, namely 'biographical disruption', 'coping', 'strategy', and 'liminality'. As discussed in Chapter 3, these concepts are used in coding in the thematic analysis. Biographical disruption indicates the negative experience of prostate cancer, which includes the experience of disruptive effects and challenges that may change a participant's identity. On the other hand, coping and strategy indicate a participant's adaptation responses towards the negative experience of his prostate cancer. Lastly, liminality represents the experience of uncertainty, deterioration, or a transition of a participant's identity.

On analysis, five main themes were revealed from an analysis of the participants' stories, where each theme discusses a part of the prostate cancer experience. These themes will give a clearer picture of prostate cancer experience among the participants. The first theme is 'the radiotherapy experience: it was not only about filling bladders'. In this theme, I present more details about the participants' experiences with radiotherapy and how these experiences affected them and their lives. The second theme is 'sexual dysfunction: did it really matter?' and discusses the participants' experiences with sexual dysfunction and shows how this

experience varied between the men. The third theme is ‘the experience of other complications: it became troublesome’. I talk about the experience of other common complications and body changes that resulted from cancer treatments. I present in this theme some examples of the disruptive impacts and difficulties that were evident in participants’ experience with these complications and body changes. The fourth theme is ‘the experience of liminality: how I became like this’. The liminality here does not reflect the experience of uncertainty, but it reflects the transition of identity. Therefore, this theme presents how the significant impacts of prostate cancer and its treatments on some men’s lives caused this shift in their identity. Lastly, the fifth theme is ‘family involvement: they were also part of this experience’. In this theme, I discuss the influence of family involvement in the participants’ experience with prostate cancer.

## **5.2 The radiotherapy experience: it was not only about filling bladders**

This first theme revealed more about the participants’ experiences with radiotherapy. As noted in Chapter 4, the disruptive experience from radiotherapy emerges with the occurrence of its procedure. The majority of the participants had negative experiences from the radiotherapy procedure. They had significant physical discomfort and tiredness from drinking large quantities of fluids and having daily radiation sessions. Besides that, most of them expressed how they were anxious, stressed, and annoyed by having to hold their full bladder before and during each session. Some of them had micturition incidents during sessions, which caused psychological distress and affected their self-esteem. For Participant 8, the impacts of this procedure went beyond the physical and psychological to significantly affect and disrupt the religious aspect of his life:

The radiation [sessions] were scheduled with the time of Ramadan [the fasting month]<sup>10</sup>. There was no duty [no work or radiation session can be done] after sunset. I collapsed [an expression of shock] on the day they told me [about the radiation schedule]. I started crying. I am a pilgrim and I cannot fast Ramadan. I was very upset. (Participant 8)

This participant’s radiotherapy period was scheduled in Ramadan, the fasting month for Muslims. As previously discussed in Chapter 2, Muslims in Ramadan are not allowed to eat or drink from sunrise to sunset, although some people are excused from fasting, such as sick people. However, because of the instruction to drink copious amounts of fluids before having

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<sup>10</sup> [ ] indicates my comments or participants’ words that need to be explained. See Appendix 8.

each radiation session, this man was not able to fast. Although being a cancer patient could be a reasonable explanation for not fasting, he was shocked and emotionally affected because of that. He pointed out that he did the pilgrimage (one of the five basics of Islamic rituals) to indicate that he is a good practising Muslim. But by not fasting, his thought of being a practising Muslim changed, which could explain his negativity towards the radiotherapy and inability to fast. Thus, it may be perceived, a standard treatment for some people is far from standard for practising Muslims such as this participant.

The disruptive impacts from radiotherapy or its procedure also had a negative influence on some participants' lives in terms of social activities and work. For example, Participant 6 and Participant 9 stated in their stories that they had to stop their work and became homebound when they started their radiotherapy:

Whoever you are, you cannot work while having radiotherapy. I stopped work. I become unsocial. I spend most of my time at home...I cannot work. There is no money. The [financial] situation is bad. (Participant 6)

I resigned from work when I started having the treatment. I quit. Because I do not work, I [socially] withdraw. I fill my time with reading and watching sports just to entertain myself. (Participant 9)

The quotations above show that the disruptive experience from the radiotherapy and its procedure may have a major effect on an individual's ability to work, and therefore earn money to maintain his family and lifestyle. Indeed, in the examples above, the treatment forced these two participants to stop work. With no job, they both spent most of their time at home and became less sociable. This indicates that the inability to work created another psychosocial impact from their cancer treatment. For Participant 6, the inability to work built up more disruption by causing him financial difficulty, which affected his role as a provider for the family (see more in the fifth theme and in Chapter 6). For Participant 9, his strategy to overcome the impacts of unemployment was by entertaining himself in the time he is spending at home.

However, some participants could continue to work regardless of the demands of their treatment. For instance, unlike Participant 6 and Participant 9, Participant 14 stated in his story that he was able to continue working, even after having his radiation sessions:

I still work as it [cancer] did not exist. Even during the periods when I was taking radiation. You know that the radiation session is troublesome and deadly [extremely tiring]. When I finished the radiation, I did not go home. I used to go to my office and work. Sometimes, I was tired. I laid down on a couch. I took a nap for 15-30 minutes and then continued working. I never stop working. This is my nature. (Participant 14)

The participant acknowledged, as was the case for most of the other participants in the study, that radiotherapy was physically tiring. However, this participant decided to continue his work, even with this fatigue. He preferred not to stop working since working is a central part of his character. Contrary to Participant 6 and Participant 9, Participant 14 managed the disruption from the radiotherapy on himself by maintaining his job and the ability to continue working. It may be concluded that it seems likely that unemployment because of the disruption to normal life would affect the participants' perceptions of themselves and their self-worth (see discussion regarding the fourth theme on pages 121-122 for more examples of this).

Furthermore, it is well understood that radiation therapy not only kills prostatic cancer cells, but also affects or damages normal tissue around these cells. Therefore, most of the participants suffered from urinary problems during and after the radiotherapy period. These problems included frequency of urination, urgency, burning sensation with urine, urine dribbling (leakage), incontinence (no control), and nocturia. The impacts of these problems on the participants' lives varied from one to another. The participants' strategies or attempts to manage these affects also varied. For instance, 10 of the 15 participants mentioned in their stories that they experienced a burning sensation with urine, which mainly caused them physical discomfort. To reduce this discomfort, most of them took medications for it, increased fluid intake, or used herbs. Participants 1 and 10 are good examples:

During the [radiation] treatment period, the burning [sensation with urine] was strong, but without blood [in urine]. The doctor told me that it was from the radiation. So, I started drinking a fizzing solution [a medication]. When I am at home, I drink much. In the morning, my wife and I boil parsley and drink its water. (Participant 1)

I use Omnic [a medication]. I also use Artemisia [a plant]. I drink two cups of it with tea, one in the morning and one in the evening. (Participant 10)

The physical impact of radiotherapy was also seen in the case of nocturia. Participants 8 and 15, as an example, stated in their stories, how this problem interrupted their sleep many times during the night. Participant 15 offered a brief but revealing observation when he stated: "I urinate a lot. I go [to the toilet] five or six times at night...I do not drink much, a litre at maximum", a problem that was further related by Participant 8:

I cannot sleep. I have to go to the toilet many times. I nap for an hour or two and then wake up. I feel like an imbalance in my body when I feel a bit of urine in my bladder. Till now, I cannot sleep. (Participant 8)

Both participants indicated at the time of their interviews that they were still suffering from nocturia. The persistence of this problem on these men affected their sleeping pattern, which

possibly caused physical tiredness and distress. Participant 15 limited his daily fluids intake hoping that it would reduce his need for using the toilet at night. Limiting his fluids intake was his attempt to overcome the impact of his nocturia.

The impacts of the urinary problems went beyond the physical discomfort to affect the religious aspect of participants' lives. Two thirds (10 out of 15) of the participants revealed in their stories that they experienced urinary dribbling and incontinence, but as noted in Chapter 4, these radiotherapy complications caused a major distress for several participants in terms of maintaining their ritual purity and performing the obligatory five prayers. Participants 8 and 13 offered two good examples of this issue:

When it [urine incontinence/ dribbling] happened, I had to change my underwear or do ablution again to pray. In every prayer, I had to change and do ablution...It is still happening. I make sure I am still [pure]. Sometimes, I do ablution at Maghrib [sunset prayer] and stay pure till Isha [night prayer]. I also delay Dhuhr [midday prayer] to pray Asr [afternoon prayer] with the same ablution. (Participant 8)

Sometimes, there is leakage [urine dribbling], like a drop. As you know, I change my underwear and do ablution when it happens. I do ablution and perform the prayer as usual. It does not affect me much. It happens occasionally, like once in a month or two. (Participant 13)

From the quotations above, the urinary dribbling, or even incontinence, caused difficulties for these two participants to maintain their ritual purity. However, the disruption experience from these problems varied. Participant 13 stated that his urinary dribbling did not cause such difficulties as it happened only occasionally. Yet, the incontinence or dribbling incidents frequently experienced by Participant 8 made him change his underwear and do ablution before each prayer. Therefore, the disruption experience from his urinary problems was clearly significant on an important religious aspect of his life. To overcome the impacts of these problems on ritual purity, Participant 8 (and some of the other participants) managed the ablution timing and performed two prayers within a short period. Other participants used a tissue to keep their underwear clean instead of changing it in the case of urinary dribbling. So, overall, the experience of urinary dribbling or incontinence can add a specific religious disruption to the experience of prostate cancer among a group of religious practising Muslim men.

The negative experience of the inability to hold or control the bladder (incontinence) therefore, caused more disruption for some men by affecting their social engagements and limiting their social activities. This was obvious in Participant 7's story:

I cannot hold it [bladder/urine] for long. I do not drink much fluids, so I do not need [using the toilet]. I have also limited my visits. If I want to visit my brother, for example, I will keep asking for the toilet 4-5 times in an hour. The same thing is when I am in a meeting with men...I am 70 years old. I frequently use the toilet while I am sitting with other old men. These are little things, but it has its influence. It is *painful*. I feel I am gradually worn down. (Participant 7)

The inability to hold or control the bladder made this man frequently use the toilet to avoid any incontinence incidents. Consequently, it would cause him embarrassment by constantly asking to use the toilet, and the social embarrassment that accompanies such frequent requests. Therefore, this participant attempted to manage this problem by reducing his fluids intake and limiting his social meetings and visits. For other participants, their strategies to adapt to their bladder problem were by marking the time needed before going out, or not being embarrassed and using the toilet when it is needed. However, this participant showed his anger and psychological pain from this urinary issue. He highlighted his age as an elder possibly to indicate that the negative experience of this problem had disrupted his self-image as a senior man, who should be able to control himself and act like a normal older man among his peers.

Besides the inability to control normal bladder function, Participant 7 and Participant 15 suffered from loss of control on their bowels as a side effect of radiotherapy. As a result, highly negative and disturbing psychosocial impacts occurred with their experiences of this treatment, as illustrated in the next two excerpts:

During and after the radiation [radiotherapy], I used to wear two pairs of trousers. It was because I unconsciously leaked [lost control] from back and front [referring to bowels and urine]. So, if one got dirty, the other one would be clean. I then would take a shower and put the dirty one [trousers] in a rubbish bag. My wife cried when she saw me throwing the dirty clothes. I did not let her wash them...Now, I can control my bowels but not on urine [bladder]. (Participant 7)

During the [radiotherapy] treatment, I had a general weakness, like no control on urine [bladder] and even sometimes on the bowels. *Why I was like that?* I mean losing control of my urine and bowels. *It annoyed me a lot.* One day, it [loss control of bowels] happened while I was eating in a restaurant. I left the restaurant. It was a very annoying and disgusting experience...I now can control [the bowels], but not urine [the bladder]. (Participant 15)

It was clear in the experience of Participant 15 that the incident of bowel incontinence caused embarrassment since it happened to him in public. For Participant 7, his strategy to avoid this embarrassment was by wearing two pairs of trousers so his incident would not be seen to the public. It may be concluded that, like the experience of the inability to control the bladder, the experience of bowel incontinence could also seriously disrupt these men's image as adults. This disruption might remain even though they eventually were able to control their bowels,

because they were still unable to control their bladders. Subsequently, their daily lives were clearly disrupted, limiting the engagement with any social activities.

To summarise, this theme demonstrates that the disruptive radiotherapy experience either from its procedure or its complications on the participants' bodies went beyond the physical symptoms and impacted on the psychological, social, and religious aspects of their lives. This procedure was a challenge to rituals like fasting and the participants' sense of being a practising Muslim. Similarly, the disruptive experience of the common urinary problems during or after radiotherapy caused religious hardships, inability to maintain the ritual purity and perform the five obligatory prayers. For some participants, the significant disruption from the radiotherapy experience disturbed their ability to work and/or to control their bodies. This consequently affected their social engagements, self-esteem, self-worth, and even disrupted the self-image of being mature men. On the other hand, this theme shows that most of the participants faced difficulties from their experiences with this treatment and attempted or used strategies to manage the disruption on themselves and their lives. Some were able to manage and adapt to this disruption while others were still struggling with it. This suggests that the participants' experiences with radiotherapy were mixed with other major biographical events involving disruption and adaptation.

### **5.3 Sexual dysfunction: did it really matter?**

This second theme discusses the participants' experiences with their sexual dysfunction as a part of their experience with prostate cancer. All participants shared in their stories that they experienced various sexual dysfunctions that ranged from barely affecting them to more significant effects. They stated that their sexual function was affected by their radiotherapy, and it frequently got worse with the hormonal therapy. Mostly, erectile dysfunction and dry ejaculation were reported after their radiotherapy, while a complete loss of erection and sexual desire were experienced when having hormonal treatment. In some participants' cases, hormonal therapy caused changes in their genitalia, such as shrinking in the length of the penis and/or the size of the testes. Regardless of the sexual dysfunction or genital change, the participants' responses to their experiences varied. As briefly noted in Chapter 4, there was a group of the participants, who coped with and adapted to their sexual dysfunction, and another group of men, who were significantly affected by the same experience with this dysfunction.

Two thirds (10) of the participants expressed in their stories that they were less worried or even unconcerned about their sexual dysfunction. Most of them highlighted their age or presented

themselves as elders to show their acceptance and their sexual dysfunction as a part of their aging process. Participants 3 and 11 offered examples of this:

Honestly, the sexual relationship has reduced a lot. I mean I do not feel any [sexual] desire or interest. There is no erection. Plus, the age has its role. I am 78 years old. It is over ((laughing)). My wife is in her seventies too. The sexual relationship is not an issue to her ((laughing)). She accepted the [new sexual] situation. Her relationship and treatment for me are still the same. So, I am okay. (Participant 3)

You know age is a factor. You will not be sexually active as same as in your youth. So, age has its influence on me and on my wife. But particularly with hormonal therapy, I have lost 100% of my sexual desire. I do not feel that I need sex. In addition, it [hormonal therapy] has biological effects. There is no erection. My penis has shrunk. I try to find it, but I cannot ((laughing)). Of course, I have not taken [medications] for these sexual problems because I am old. (Participant 11)

Both participants pointed out the significant impacts of their cancer treatments on their sexual function, but at the same time, they stated that their age also contributed to the dysfunction. This suggests their acceptance of their new sexual condition since they believed that it would eventually happen with or without their cancer treatment. Adding to that, these two participants and some others in the same group were laughing when they were narrating their experiences with sexual dysfunction. Their laughing may seem like a strategy to hide deep discomfort from this experience or to reflect their generally relaxed coping and adapting to it, but it may also just be because they were addressing a socially ‘delicate’ topic with someone.

Participant 9 had a similar reaction of appearing not to be worried or concerned about his sexual dysfunction. He had another reason, besides his age, to justify his reaction:

The doctor told me about the hormonal injections before I had them. He said that there would not be any stimulation in this area ((pointing to his groin)) and these injections would kill [severely affect] my sexual desire. I told him: “Do not worry. I have three sons and four daughters. So, I do not care. I do not want kids anymore”...Most of the elders have potency problem. I am old. So, it is not a big deal for me. (Participant 9)

This participant directly stated that his sexual dysfunction was not a big issue for him because it was a common phenomenon among men of his age, as noted by other participants earlier. He also outlined through his conversation with his doctor that he was not worried about having sexual dysfunction since he had seven children. Here, he possibly wanted to highlight what was for him one of the main purposes of sexual function, which is reproduction. Thus, losing this function for him might not cause much disruption since he had already completed his family.

Participant 8 and Participant 10 added other reasons and explanation to clarify why they were less concerned about the sexual practice at their age as same as their experiences with sexual dysfunction:

There are sexual problems. There is no [sexual] desire. There is a weak erection, *very weak*. Plus, I am old and she [his wife] is old. She is adapted. We both are bored ((laughing)). Sometimes, I feel shy about having it [sex]. (Participant 8)

Truly, my testes have become smaller as a side effect of the hormone [therapy]. Of course, there is no sexual life. It is not with my hands ((laughing)). There is no testosterone with hormonal therapy. So, there is no gasoline for sex...I have not tried [having sex since then]. It will cause embarrassment to me and to my wife if I try and end up failing. Many old people do not practice sex either because they and their wives are shy to ask or because they think of sex as a shameful act to do it at this age...We [he and his wife] are satisfied. We hug each other each night and then sleep. (Participant 10)

The quotations above show that these two participants and their wives coped with the new sexual situation. It also presents their personal, and maybe Islamic, cultural perceptions about sexual practice among the elderly. Participant 8 directly and Participant 10 indirectly referring to other old men indicated that they would be shy to ask or practice sex at their age. Consequently, their interest of practising sex would be reduced, which was noted in Participant 8's quotation "we both are bored". From a different angle, their shyness or avoidance of practising sex could be from their fear of embarrassment in front of their wives if they failed to have an erection. It was clearly noted in Participant 10's quotation when he did not try having sex to avoid the embarrassment from his dysfunction in front of his wife. This indicates that even though these men showed their coping with their sexual dysfunction, there could be a disruptive psychological effect from this experience. In turn, Participant 10 tried to maintain his intimate relationship with his wife by hugging instead of having intercourse, considered a strategy to manage the disruptive effect of this experience.

Overall, the experience of sexual dysfunction did not matter to this group of the participants, but most of them were concerned about their partners. Some of them responded like Participant 10, and adapted strategies to maintain their sexual life. Participants 5 and 15 are examples of this:

I need sexual arousal to make the [sexual] connection. One-time, I took a pill [possibly Viagra] and I got a severe headache, high [blood] pressure, and stress. I forbade myself from trying it again. I prefer not to have sex. But I do it for my wife so that she does not miss anything [satisfying her sexually]. She is actually a wonderful wife. Her only concern is my health, being in a good health, and nothing else. (Participant 5)

I have stopped [having sex] for more than a year. I have not tried. There is no erection or [sexual] desire. I am worried about my wife that she is not [sexually] satisfied. We flirt and hug each other. We say we will compensate once I recover. But what if I will not [recover]. She is human and has a right to enjoy her life. I do not mind breaking up, but she will not agree. (Participant 15)

Hugging, flirting, or using a sexual stimulation like medications were all strategies being adopted by both participants and their wives to minimise the disruption from the sexual dysfunction experience and to keep their sexual relationship active. Yet at the same time, both showed in their narratives that they were still concerned about their wives, i.e., if they were sexually satisfied or not. Their concern about their wives suggests that their sexual dysfunction challenged their role as a husband, namely someone who should be sexually able to satisfy his wife. This perhaps indicates that the experience with sexual dysfunction, as a part of the prostate cancer experience, was not only about these men but also about their intimate relationships with their wives (and possibly others - see more about this issue in the fifth theme in this chapter on page 127). In turn, these participants' wives showed their support, partnership, and love for their husbands throughout their responses to sexual dysfunction. The wives' support was also evident earlier in the other participants' quotations when these men stated how their wives coped, accepted, and understood their new sexual situation.

In contrast to the above, there was a group of participants who were severely affected by their experiences with sexual dysfunction. The experience with sexual dysfunction was clearly a more disturbing issue for them. A more definitive example of this was evident in Participant 7's story when he recalled the impacts of his cancer treatments on his sexual function and relationship:

I was deprived of my sexual relationship, which is important to a man. I have lost potency after 3 months of taking the radiation treatment. The [sexual] desire has also diminished. I mean my wife is beside me and *I am not*. It psychologically has a big impact. We used to have sex once or twice a week and suddenly I found myself [a long silent interval] *nothing*...The most thing that would kill a man is being diagnosed with prostate cancer and being [sexually] away from his wife. A man can bear anything except losing his manhood. It is hard, especially when his wife looks at him. I have been like a rag beside my wife for 6 years. She has not tried to get closer to me [pointing to any sexual interaction] because she knows that it will not arouse me. Women have their [sexual] rights as wives. I have frigidity. It is not because I do not want [sex]. It is because I cannot. With no erection or [sexual] desire, there is no sexual relationship, [a short silent interval] it is over. (Participant 7)

The disruption from the experience with sexual dysfunction was clear in this man's case resulting from a significant change in his sexual life. He indicated that he was sexually active before his diagnosis of prostate cancer, but with the cancer treatments, he described himself as

a “rag” to declare how he became sexually inactive and weak. The major change in his sexual practice had a significant psychological impact on him and his sense of being a man. He directly stated that his sexual function (potency) was a part of his manhood, which suggests the possible negative impact of this experience on his masculinity (see more about gender identity in Chapter 6). He also added that he, like other participants, was concerned about his wife’s right to be sexually satisfied. Again, this created a significant challenge for him since he could not do anything about it. He, as a husband, would not be able to meet his wife’s sexual needs with his impotency. This can also demonstrate the disruptive impact of this experience on the marital relationship and the sexual role as a husband.

Like Participant 7, Participant 2 revealed in his story a similar disruptive experience with his sexual dysfunction:

I used to have sex once or twice a week. I stopped having intercourse once I started taking the hormonal injections with radiotherapy. There was [sexual] desire. I had tried many times to sleep with her [an expression of having sex], but it [penis] did not stand up [no erection]...I *despised myself*. I was entirely affected. I wanted to be like any man who has normal sex with his wife... When men, who I know, asked me about my sexual ability, I told them it was normal. But it was not. I tried different types of sexual supplements, honey, meat, etc. But all did not work. I asked my doctor and he said: “after the radiation and the hormonal injection. You need time”. I am actually back to normal after a year...I can have intercourse with my wife but not with a full erection or ejaculation. (Participant 2)

This participant indicated the significant impact of his cancer treatment on his sexual function, especially having an erection. He stated that he tried many times to have intercourse with his wife, but it did not work due to his impotency. He attempted to increase his sexual ability (erection) by taking sexual supplements, natural products like honey, and even having a special diet. All his attempts failed, and this significantly affected his sense of himself as a normal man. He hid his sexual dysfunction from other men, which was most likely from his fear of embarrassment or to be seen less manly among them. This suggests the negative influence of his sexual dysfunction experience on his masculinity (see more examples in Chapter 6). The participant eventually asked his doctor about his problem and was reassured that his sexual function would return post-treatment. Indeed, his sexual function mostly recovered, which indicates that the disruption from this experience did not last for too long, but more importantly, allowed him to feel restored both sexually and as a man.

The same negative experience with sexual dysfunction was also present in the stories of Participant 4 and Participant 6. Like Participant 2 and Participant 7, they were also significantly

affected by their sexual dysfunction. However, unlike Participant 2, they experienced difficulties in terms of recovery from sexual dysfunction, and sought medical advice regarding this issue:

((With an angry tone)) I have not had sex for 2 years ((dusting his hand)) [an expression of having nothing]. I do not have any desire for sex or into any female. *I do not know why*. Is it from these hormonal injections? *I do not know*. [A short silent interval] I will be ashamed if I have intercourse with my wife and I end up *with failing*...My wife has accepted the [new sexual] situation with a big heart. I swear by Allah that she is the one, who consoles me...I am afraid to take Viagra because I have heart problems. *I am shy* to ask or tell them [doctors] that I have not had sex for 2 years. He [his doctor] is always with his assistants, who are females. *I cannot ask*. I blush. (Participant 4)

My sexual status is bad, *Zero*. I mean I barely urinate [pointing to poor erectile function]. There is no [sexual] desire or ability. I am deprived of sex...I still see myself as young, not an old man. Even though I am over sixty, there is a sexual desire that needs to be satisfied. I do feel for my wife. Sex is not a problem for her, but it is a problem for me. It lowers your prestige, your masculinity. My wife has not shown me either with a word or a sign that I have lost something [referring to his sexual function]...*I cannot do anything*. I want to take Viagra or a pill, but I am afraid that it would cause me problems in the heart or brain. I have not had a chance to talk with my doctor without the presence of females. *I could not talk or ask him*. I could not be alone with him. Till now, my sexual ability is completely non-existent. (Participant 6)

It was obvious, in both participants, the significant impact of their cancer treatments on their sexual function and their abilities to do something about the problem. Even with their wives' support and love, the negative psychological impact of the experience with sexual dysfunction still existed. In the case of Participant 6, he explicitly mentioned that he still saw himself as young, unlike members of the first group who more readily accepted their older years, which made the sexual function important to him. Likewise, Participant 4 was also 60 years old at the time of his interview, and he might have considered himself 'young' too. This could explain both Participant 4's and Participant 6's expressions of anger and frustration towards their sexual dysfunction.

Furthermore, these two participants wanted to find a solution to restore their sexual function. They stated that they had a fear of trying any medication without medical advice because of their potency and possible side effects. Even more problematic, in the presence of female healthcare providers, they were not able to ask for advice or talk with their doctors in private about their sexual condition. Here, these two participants experienced a kind of disorientation and uncertainty about their sexual condition, what to do, and the future of their sexual life. This disorientation and uncertainty reflected their experiences of liminality, which was clear in Participant 4's case when he repeatedly said: "I do not know". Finally, the experience with

sexual dysfunction also had a negative impact on masculinity as clearly noted in Participant 6's quotation: "It lowers your prestige, your masculinity". This indicates again that the negative experience with sexual dysfunction could disrupt the sense of being a man. More about this important issue will be discussed in Chapter 6.

This theme has presented more details about the experience of sexual dysfunction among the participants of this study. It shows that the participants' responses and reactions towards this experience varied due to the influences of their personal, Islamic, or cultural perceptions of sex and sexual dysfunction. Most of the participants considered themselves old, and by their own reasoning, would probably have this dysfunction with or without cancer. Some of them considered practising sex at their age to be inappropriate and even shameful. With these perceptions, they were less concerned about having sex or losing their sexual function, therefore their experiences with sexual dysfunction were not viewed as a negative for them. They coped and accepted their new sexual condition. On the other hand, sexual function was important to other participants either because they considered themselves young or because it (potency) was an important part of their sense of being a man. The negative experience and disruption caused by their sexual dysfunction was obvious in their stories.

In addition, this theme demonstrates in many participants how the sexual dysfunction experience caused a challenge in terms of the ability to meet the perceived sexual needs of their wives. At the same time, it outlines the significant role of their wives' support and love for their husbands in easing the disruptive impacts of this experience. Overall, many of the participants and their wives collaborated and used a range of strategies to manage these disruptive impacts and maintain their sexual relationships. But for some of them, the disruption from sexual dysfunction experience was significant and they were not able to accept it, even with their various attempts to resolve the problem, and their wives' support. This suggests that the sexual dysfunction experience, as a part of the prostate cancer experience, was for most participants, also subject to various degrees of disruption and adaptation.

Lastly, this theme highlights that the topic of sex and sexual dysfunction for some participants was shameful and difficult to discuss in front of others, especially females. This, of course, became a barrier for these men to address their sexual issues to medical staff in the presence of female healthcare providers. Therefore, the gender of healthcare providers can be an important factor for a group of Muslim men with prostate cancer in terms of addressing their health concerns and receiving the support they need.

## 5.4 The experience of other complications: it became troublesome

Adding to the previous two themes, this theme demonstrates more about the participants' experiences with prostate cancer by addressing their experiences of other complications from their cancer treatments. Besides the common urinary and sexual problems, most of the participants experienced complications and physiological changes that included hot flushes, weight gain, and general fatigue. The disruptive experience with these complications and bodily changes were obvious in some participants' stories. In the case of the experience of hot flushes, Participant 6, as an example, revealed his negative experience in his story:

Sweating, hot flushes are very discomfort. My belly and breasts have become bigger. Sweating, hot flushes come 10-11 times day and night, in summer or winter. I do not use tissues. I use a face towel [an indication of the excessive sweating]...The sweating problem *kills* [severely annoys] me. [It happens] even in people's houses. I keep wiping [the sweating]. One-time while I was walking in a shopping mall, I started sweating. I felt tired and dizzy. People came for help and they started giving me tissues...I was entirely *disturbed*. *I felt weak*. I am trying to overcome this feeling. I try to hide it from people to avoid their sympathy and their pity look. (Participant 6)

This particular man expressed how his experience with hot flushes caused him severe physical discomfort due to excessive sweating and its frequency. He added that he did not have the ability to control it since it was happening in front of people and in different places. There was psychosocial discomfort for him, as this experience caused embarrassment and made people feel sympathetic towards for him. With all the negative experiences from hot flushes, the embarrassment, and people's sympathy, this participant stated that he was significantly affected and felt weak. However, his strategy to contain this impact was by hiding his sense of weakness in front of others, playing down the problem by avoiding eye contact.

Weight gain was another side effect from hormonal therapy that had disruptive impacts in some participants. Participants 9 and 13 are examples of this:

I feel that I have gained weight. I am trying to reduce my food [intake]. Although I do fast, I still have gained weight. I was 80 kilograms. Now, I am 85 [kilograms] and it is still increasing. It annoys me. It causes a bit of difficulty. I mean with this belly ((pointing to his abdomen)), it causes discomfort while doing prayers. (Participant 13)

Obesity, there is no doubt about it. I am suffering from this belly, this [weight] gain. It became a *troublesome* ((pointing to his abdomen and how big it has become)). I do a [diet] regimen. I want to reduce [this gain]. I should reduce food [intake] and do exercise. But there is no energy to walk or [to do] sports. (Participant 9)

The quotations above indicate that there was a significant change in the two participants' weight and how big their abdomens had become. Their annoyance from their weight change

could reflect the physical or psychological impact of this change on them. For Participant 13, he outlined that the significant increase in his abdominal size caused him some difficulty in the prayers' movements, such as bowing and prostrating. This suggests that his weight gain had a religious impact by causing him physical discomfort while performing his prayers. However, both participants highlighted their attempts to decrease their weight by reducing their food intake through a special diet regimen or fasting in an apparent strategy to manage the negative impact of their weight gain. Moreover, Participant 9 declared another strategy to reduce his weight, which was by doing exercise, although he was not able to do it since he had no energy, which was another treatment complication, i.e., general weakness.

General fatigue or weakness was another complication reported in some participants' stories. This complication was most likely a result of radiotherapy or hormonal therapy since the hormonal therapy can decrease muscle strength. Participant 4 was one of the men who suffered from feeling weak and idle:

There is indolence. Sometimes, I feel that my legs cannot carry me. One-time last March, I fell down while I was walking. I was only carrying a laptop bag. *I did not believe that...Has my body weakened to this level...*I easily get sweaty and tired. I am always idle. (Participant 4)

This participant used different words (e.g., 'indolence', 'idle', 'easily getting sweaty' and 'tired') to indicate his experience with fatigue or feeling physically weak. His fall shocked and surprised him due to the significant change in his body strength. The experience of this body change reflected the disruption of his cancer treatment, where this disruption might not only affect his daily activities, i.e., walking but also his sense of himself (see his example in the next theme). The persistence of feeling idle most of the time suggests the continuity of the disruptive impact of this experience on him.

Apart from the experience of hot flushes, weight gain, and general weakness, some of the participants experienced other unique complications from their cancer treatments. For example, Participant 9 revealed in his story his suffering from back and pelvic pain after completion of his radiotherapy:

After a month or two from completion of radiotherapy, I started having pain in all this area ((pointing to his pelvis and back)). I currently suffer from this pain. It is mainly in my back and it goes down to my knees...I cannot pray without sitting on a chair. Of course, I take painkillers. They [medical staff] prescribe painkillers for this pain...Now, I cannot walk 500 meters because of the pain...Until now, I am not back to my normal because of the pain. It is *troublesome*. (Participant 9)

This participant was the only participant in this study who mentioned suffering from pelvic and back pain after radiotherapy. Besides the disruptive impacts on his social and daily life, as he could not walk far, his experience of this pain caused him a religious difficulty. The pain would cause him severe physical discomfort if he normally performed the prayers' movements, such as bowing and prostrating. This explains why he needed the aid of a chair for praying. These disruptive impacts on the physical, psychosocial, and religious aspects of his life have continued even though he used painkillers to control the pain. This could explain his emphasising that his pain experience was troublesome.

Participant 15 was another example who suffered from a unique complication after radiotherapy that caused more disruption to his cancer experience:

Now and as complications from radiotherapy, I have colon ulcers and continuous bleeding. Whenever there is bleeding, there is pain and it increases with walking. I suffer a lot. I am tired of the pain. They [medical staff] have prescribed Pentasa suppositories to reduce the pain...It [the radiotherapy complications] has stopped me from working, even my social activity. I mean my life has become so limited. Most of my time is at home. I try to go out. I easily get tired and it causes me embarrassment. Yesterday, I thought I was good, so I went shopping with my wife. While we were at the shopping centre, I fell to the ground. I *could not walk* because of the severity of the pain. People brought a wheelchair and helped me into my car...Sometimes, I feel frustration and hopelessness. I feel I am weak. Death is better than living like this. But I say to myself that I need to be patient. I am searching for a cure to get rid of it...I mainly eat boiled vegetables and less meat...These complications *truly annoy* me a lot. *It is really troublesome*, especially from the pain when I walk. (Participant 15)

The participant's disruptive experience with colon ulcers, bleeding, and rectal pain had significant impacts on a range of aspects of his life. Besides the severe physical pain and tiredness, this experience had limited his social activities and his ability to work. This consequently had a significant psychological impact on him, which was pointed out through his feelings of weakness, frustration, and hopelessness. He tried to manage the impacts through using medications, changing type of diet, limiting social activities, and adapting the Islamic value of patience to overcome the negative feelings from the experience. With all his attempts of adaptation, the radiotherapy complications were more disruptive on him and on his life. This was obvious in his declaration how this experience with these complications was troublesome.

In summary, this theme has highlighted other common and uncommon complications from the prostate cancer treatments that have disruptive impacts on the participants' lives, besides their experiences with urinary and sexual problems. It has presented how the experiences of complications such as hot flushes, weight gain, general weakness, or unique complications like

bone pain and colon complications after radiotherapy had a significant impact on some participants' bodies, which negatively affected different aspects of their lives. Apart from the physical discomfort and body changes, these complications had psychological, social, and sometimes religious effects on these participants' lives and in turn could cause more disruption from this illness experience. On the other hand, this theme has demonstrated that some of the participants tried a range of strategies and attempts to manage the disruption from the experience. This, again, suggests that the experiences with prostate cancer among the participants were mixed with disruption and adaptation.

## **5.5 The experience of liminality: how they became like this**

As discussed in Chapters 2 and 3, the concept 'liminality' is not only used to reflect the experience on disorientation and uncertainty but also the transition status on the identity. In this theme, this concept is used to reflect the transition of some participants' identities that have been revealed in their cancer stories. From the 15 participants, three participants had directly presented in their stories how their cancer experiences caused a significant negative change to themselves in the way they used to be before cancer. These were Participants 4, 9, and 15.

Participant 4 highlighted an experience that concurs with the concept of liminality when he talked about his experience with general weakness:

I used to be *very active*. I used to fix any faults that happen at home. I swear by Allah that I am familiar with electricity, carpentry, and plumbing. I used to fix everything by my hands. Now, ((with an angry tone)) I cannot knock a nail. I easily get sweaty and tired. I am always idle. *Has my body weakened to this level?* (Participant 4)

This quotation is an extension of the quotation that was mentioned earlier in the previous theme about his fall incident and his continuous feelings of being idle. In this quotation, this participant outlined how he was very active and good at manual skills. But with the negative impact of the cancer treatment on his body, he became inactive and unable to demonstrate any physical effort by saying "I cannot knock a nail". This transition from a skilful and active man to a weak inactive man indicates the experience of liminality and the negative impact of his cancer experience on his sense of self.

Similarly, Participant 9 revealed in his story the significant negative change on the man he used to be before cancer:

I was an athlete. All of my life, I used to swim, play, and walk for long distances. Now, I cannot walk 500 meters because of the pain. This is not my norm...I was always active. I still feel that I have energy and strength. But since I diagnosed with this disease,

it is over. It limits my energy, my work, my determination [a short silent interval]. I am an engineer. I used to do things and fix the home's electricity with my hands. Now, I cannot lift anything heavy. This disease destroys the strength ((expressing anger and frustration by resting both hands heavily on thighs and knees)). There is no doubt about that. I get *tired*. I am not as I was before. In the end, I try to convince myself that I am old. (Participant 9)

The disruption from prostate cancer and its treatment complications on this participant's body strength also negatively changed his life and sense of self. This participant compared himself now with himself before cancer and pointed out that he was once a physically fit (an athlete), energetic and a skilful man before his cancer. But now, he could not work, practice, or manage his previous routines, which all were part of his self-awareness and his life. As a result, his 'sense of himself' was affected. He stated that he is not the same man anymore, which reflected an obvious biographical disruption and the liminality resulted from his cancer experience. In the end, this participant attempted to reformulate the disruption of his sense of self by convincing himself that he had become old. This may be considered a strategy to make sense of and manage the disruption from this experience on himself.

Lastly, Participant 15 was another example of who presented in his story the negative transition of his sense of himself due to the complications of the cancer treatment:

I see in myself that I have to work, and I do have the energy to work. But this [illness] situation has stopped me. It is not from cancer itself. No, it is from the radiotherapy complications. It [the radiotherapy complications] has stopped me from working, even my social activity. I mean my life has become so limited. Most of my time is at home...Sometimes, I think about myself as a disabled person...I am not a normal person who [normally] practices his life, works, comes and goes. I used to travel a lot. I used to wear a suit with a tie. I used to shave every day. Now, everything has changed. I do not wear a tie. I shave once every 5-6 days. (Participant 15)

As mentioned in the previous theme, this participant suffered from colon ulcers, rectal bleeding, and severe pain as post-radiotherapy complications. The experience of these complications had a significant disruptive impact on him and his life. From the quotation above, this participant highlighted how this experience stopped him from working and forced him to become homebound. This consequently affected him psychologically, his self-image, and sense of self-worth. The man was a businessman before cancer, who used to work, look elegant, and travel a great deal, but with the radiotherapy complications, he could not work again and live his life as it was before. He described himself as a "disabled person" to reflect how his self-image and self-worth had been disrupted. The huge change of his sense of self from a normal, successful, and independent man to dependent (disabled) homebound man

indicates the liminality experience and an obvious biographical disruption that resulted from the experience with treatment complications.

Apart from the three participants above, there were other participants (in a similar fashion to the participants of the second group in Chapter 4) who were also severely affected by the disruptive impacts and challenges of the cancer experience. These participants did not directly indicate in their stories about the transition of their identity as did the three men above. Some of them, like Participants 2, 6, and 7, stated in their experiences with sexual dysfunction that they felt less manly comparing themselves with themselves before this experience or with other men in their society (see the second theme of this chapter). In these participants' cases, they also experienced a kind of liminality in their gender identity due to their sexual dysfunction. On the other hand, one group of the participants in this study had contained or managed the disruptive impacts and challenges of the cancer experience (as noted in the previous three themes of the chapter). Thus, the transition of identity or the negative impact of the prostate cancer experience on identity was not entirely clear in their stories. This suggests that these participants might not have experienced this negative transition, or perhaps had reformulated the biographical disruption in a positive way (like their responses to sexual dysfunction) by describing, and possibly regarding themselves as old men.

To summarise, this theme has demonstrated more about the negative influence of the cancer experience and its treatment complications on some participants' identity by capturing the transition of the identity (liminality) in this experience. Besides the previous three themes, this theme shows that the more disruption cancer treatments have on the man's body and on the aspects of his life, the more impact on the sense of identity in terms of self-esteem, self-image, self-worth and perhaps even the sense of being a man (see more about gender identity in Chapter 6). This, as a result, could cause a change and a transition to the man's identity. Through the three examples above and possibly in others, this theme indicates that this transition moves mainly towards the negative side along with the disruption effect. Nevertheless, it is important to note that the material in Chapter 4, and the previously described themes have shown that a group of participants managed and adapted to the disruption effect of their cancer experiences. In the case of these men, the negative impact of the prostate cancer experience on their identity or the negative transition of the identity was not clear in their illness stories. Thus, they possibly maintained their sense of themselves as they adapted to this illness experience, or perhaps adapted in ways that were less overt.

## 5.6 Family involvement: they were also part of this experience

Most if not all the participants talked about their families throughout their illness stories, especially in and after the diagnosis period. In this theme, I explain more about family involvement in the cancer experience and how this involvement had an influence on the participants' experiences with this disease.

Family involvement became a part of the cancer experience for the participants because the family has close relationships with the affected men who are fathers, husbands, heads of the family, and the man of the house. This involvement creates mutual concerns between the participants and their families. From the participants' side, their concern was mainly about the consequent impacts of their illness on their families. From the family's side, their concern seemed to indicate anxiety about the impact of prostate cancer and its treatments on their loved one. As noted in Chapter 4, the participants' concern about their families was obvious in most of the men's narratives about their diagnosis moments. These participants showed their worry about the psychological distress and emotional impact from their diagnosis on their families. Four of the men hid their diagnosis from their family members as a result. Others used different strategies and tricks of reassurance to their families when they understood their diagnosis with cancer. Here, their concerns about their families often appeared to build up more psychological distress for them and for many it became a challenge during this time to settle the family down and convince them that they were fine, even if they were not.

However, the participants' concern about the family was not only from their worry about the psychological impact of the news of their diagnosis on their families. For some participants, their concern came also from the financial consequences of cancer on them and in turn on their families. Participant 7 was one of these, he said:

The news was not easy. I felt a kind of grief. Plus, my economic status had an influence. How I would [financially] handle my [cancer] treatment. It had a big role to make me feel sorrowful. I mean I was seriously thinking that this disease would kill me. In seconds, I wished I [would] disappear and never existed. It is because I do not want to cause any pain to others. I mean *how could I put a burden to my sons*, who are freshly graduated or still at the beginning of their lives and let them carry the responsibility [of covering the cancer treatment or living expenses]. A father thinks in this way. I mean any father, not only me. So, *I was really distressed* about this issue. (Participant 7)

After hearing the news of the cancer diagnosis, this participant started to think about the financial consequence of his illness and how he could handle the treatment expenses. This, of course, created more psychological distress when he realised that his illness would cause

financial burdens to his family. He, as a father, did not want himself or his illness to cause any trouble to the family. He indicated that it would usually be common among fathers to maintain the lifestyle and level of comfort for the family. Therefore, this participant, as most of the other participants, did not want to involve his family with the illness experience because of the possible effects on their comfort, which became a major challenge of how to maintain that. At the same time, this participant, as well as others, perhaps wanted to protect the family from the negative impacts of the cancer experience on them and their lives. In this case, the participant was possibly demonstrating his protective role as a father. As discussed in Chapter 2, this role can be a place where he can demonstrate a form of his Arabic and Islamic masculinities. Here, the prostate cancer experience seems to interact with this participant's masculinity (see more in Chapter 6).

A similar way of thinking and being concerned about the illness' sequential financial impact on the family was also evident in the diagnosis period of other participants, particularly Participant 4 and Participant 10:

In the beginning, I was psychologically tired, *very distressed*. It was because my sons were still studying at universities. *Who would pay their tuition fees? Seriously*. All of them were studying in subjects like engineering with high tuition fees...Thanks to Allah for everything. The government has covered all my treatment expenses and I still work. (Participant 4)

Allah loves me because the government has covered all [cancer treatment] expenses. Otherwise, I would not be treated, and cancer would possibly spread or kill me. I cannot handle the expenses because I do not have [money]. Plus, my sons are fresh graduates, and I will not let them [pay]. (Participant 10)

Both participants, like Participant 7, thought about their cancer treatment and how they would handle their expenses. They indicated that their financial situation might not be enough to cover the expenses and their need for money might put them and their family in financial hardship. Here, these participants showed they were worried and concerned about their families becoming involved and financially affected by their illness. This suggests that the financial (disruptive) effect from the diagnosis with cancer would automatically be on the family too because these participants perhaps see themselves as culturally and religiously accountable to be the family provider (as discussed earlier in Chapter 2). Subsequently, the financial sequential impacts from the cancer experience make the family more involved in the cancer experience. As a result, it may cause more disruption to these participants by creating more psychological tensions or challenges to them in how to protect their family from any disruptive impact caused

by their cancer. Fortunately, the expenses of the cancer treatment have been covered by the government, which has reduced their financial worries on them and in turn on their families.

The mutual concerns between the men and their families did not stop at the diagnosis period but continued with their treatment periods. Most of the participants' stories showed that their families were still emotionally concerned and worried about the impacts of cancer and its treatment on their men. This indicates that the cancer experience may certainly have disruptive effects on these participants' families as well. In turn, these participants, as fathers, heads of the house, and other family related roles, tried to contain these effects. As a strategy, most of them showed their families that they were still able, or at least willing, to lessen the family's worry about them. Participants 1 and 7 are good examples of this strategy:

Emotions affect us. Sometimes, I feel [emotional] pain when my sons, daughters, or my wife are [emotionally] affected. They still feel that this disease has weakened their father and made him tired. But I remind them that we are Muslims and Allah gives us faith, which is stronger than life...They cannot believe that I do not care about this disease and it does not affect me. They treat me as a patient. They ask me to rest and stay home. I refuse that. (Participant 1)

They still look at me with a sympathetic look, especially from my daughters. They tear when they look at me. *It kills me*. It is like RPG [a rocket] enters my chest. They think that their father is over, and cancer means death...I always keep the smile on my face in front of my family. I do not want to reflect the sorrow [pain] I feel at them...I have been suffering for 6 years and everyone says that my spirits are high and very impressive- but I am weak. (Participant 7)

The quotations show that both participants' families were still affected and concerned about their father or husband. This, in turn, possibly adds another psychological disruptive impact on these participants as long as their families are still involved with their illness experience. As a result, Participant 1 tried to contain the family's concerns/emotions towards him by reminding them about faith in the way that a person should be strong and face life's hardships. He also refused to stay home or take a rest to demonstrate to them that he was still physically strong and not affected by his cancer. For Participant 7, he tried to hide his suffering and remain cheerful in front of his family to convince them that he was fine, when he was not. Subsequently, what these two men, as most likely as other participants have done in front of their families may be considered strategies to create an image to them that they were still physically and psychologically strong against their illness. This was designed to encourage the families to become less worried about their father or husband. At the same time, these two participants, could present themselves in this way to demonstrate an aspect of their masculinity as the head of the family. This concept was reflected in several of the participants' stories in

various ways, and therefore this suggests the influence of the cancer experience on Arabic and Islamic forms of masculinity (see more in Chapter 6).

It could be argued that family involvement in participants' cancer experiences did not necessarily cause the participants more psychological tensions or disrupt their perceptions of themselves as fathers or husbands. That is, the experiences could also have had a positive influence on their experiences by helping the men to more successfully manage the disruption caused by the experience. As noted earlier in the second theme of this chapter, the role and support from the participants' wives in the experience with sexual dysfunction was often quite beneficial to some participants. As also noted earlier (in Chapter 4), some of the participants' families (like the family of Participant 10) had a role in convincing him to see a specialist when he had pre-diagnosis symptoms. The same chapter also showed in the diagnosis period the role of the family in supporting their men to cope and accept their illness, such as the wives in the cases of Participant 4 and Participant 9. Even in the treatment decision-making, the family involvement had a role. Participants 13 and 15 are examples of this:

The doctor said to me that my [cancer] treatment either by removal [surgery] or by radiation and he preferred by radiation. Honestly, I did not know [what to choose]. I talked with my wife and my brothers and we decided to go with radiotherapy. (Participant 13)

The doctor said to me that I need a surgery or to take radiation. There was a group of doctors and they preferred radiotherapy due to my age...My family, my wife insisted to have the treatment. So, yes. I took the treatment. (Participant 15)

The two quotes show how the family was a part of the decision-making process. In the case of Participant 13, his family helped him in choosing his cancer treatment, alongside the medical team's recommendation. For Participant 15, the family themselves had a significant influence in supporting him going for cancer treatment.

The positive influence from family involvement was also evident during and after cancer treatment. Most of the participants revealed in their stories that they were accompanied by a member of their family to the Cancer Centre for the treatment or medical appointments. They also acknowledge the support they received from them in and after the treatment period, as illustrated in the next excerpts:

My wife does care about me. She looks after me. She meets my needs with extra. She makes me food. She prepares me water for shower. Sometimes, she washes my clothes three time or more [due to his urine incontinence or dribbling]. She has never shown me she is disgusted or tired of that. She stands by me. (Participant 6)

My wife treats me as special. She always looks after me. She cooks special food for me. She reminds me of taking my medications and of my medical appointments. She does care about me. (Participant 12)

The quotations above highlight how the support from their wives reduced the tension from the illness experience on the men. It also possibly helped in managing the disruption from this experience, such as the experience with the sexual dysfunction mentioned in the second theme.

To conclude, this theme demonstrates that prostate cancer experience can affect the participants' families by involving them and becoming part of the overall response to it. As a result, the experience could cause more challenges and maybe disruption, or provide more support and therefore reduce disruption to men as fathers and husbands. In turn, some of the participants tried to contain the experience effects on their families by using a range of reassurance strategies that make their families less worried about them. Yet, as shown, family involvement can have a positive influence on the experience and help these men in coping and managing the disruption from their illness experiences. In all, this indicates that the family were a part of the cancer experience, and their involvement had its impacts on this experience.

## **5.7 Conclusion**

The five themes in this chapter have presented a clearer picture of the prostate cancer experiences among the participants of this study. These themes highlight that prostate cancer experience can mix with (biographical) disruption and adaptation. From one perspective, they have shown that this cancer and its treatments have disruptive impacts on these men's bodies and in turn on the physical, psychological, social, and religious aspects of their lives. The more negative impacts on the man's body and his life can cause more disruption, change the sense of the self, and for some men cause a transition of their identity (liminality). These negative impacts from the illness experience can also cause more disruption to men as fathers and husbands when their families become involved. This chapter has also highlighted that most of the men tried to manage the disruption from the impacts of their illness experiences in a variety of ways, some successful, others perhaps less so. For the participants who managed the disruption reasonably well, the results were often akin to successful adaptation to their illness, and the maintenance of their senses of self. It was also shown that family involvement could have a positive role in this adaptation.

This chapter has shown the impact of prostate cancer experience on the sense of self. The next chapter will discuss in further detail the impact of this illness experience on the participants'

gender identity since their experiences have significant interactions with a range of forms of their Arabic and Islamic masculinity.

# **CHAPTER 6: PROSTATE CANCER EXPERIENCE AND GENDER IDENTITY**

## **6.1 Introduction**

This chapter is a necessary extension of the previous two chapters. In Chapter 4 and especially in Chapter 5, the findings have shown the disruptive impacts and challenges of the prostate cancer experience on the participants themselves and their lives. These impacts and challenges significantly affected their self-image, self-esteem, and self-worth, which in turn affected their identity in general. In this chapter however, the focus is on the influence of this illness experience on their gender (masculinity), a major aspect of their identity and relationships with others, and a major focus of this study.

As discussed in section three of Chapter 2, the work of Connell (2000, 2002, 2005) on the structure of gender relations demonstrate society as having multidimensional social relations between people where masculinity is constructed and performed within four main dimensions: power, production, emotional, and symbolic. In particular, the use of Connell's works helps in capturing facets of hegemonic masculinity and other possible configurations of Arabic and Islamic masculinities in Jordanian Islamic society; these can be constructed and presented within these four relations dimensions. All of Connell's works, and especially the ideas about hegemonic masculinity, are used in discussing the findings of this chapter to generate an understanding of the interactions of the masculinity of Jordanian Muslim men and their experiences with prostate cancer.

To achieve this, I present the outcomes of stage three of the analysis process. In this stage of the analysis, I used the positioning model by Bamberg and Georgakopoulou (2008) (see the data analysis subsection 3.3.6), which consists of three levels of positioning: the positioning level of the participants in their stories, the positioning level of them in relation to others within their stories, and lastly the positioning level of themselves under dominant discourses (master narratives). Through analysis using this positioning model, I was able to discover the interactions between the participants' masculinity and the prostate cancer experience. Finally, I integrate the findings of this analysis model with Connell's gender relations model to understand how the prostate cancer experience would affect gender identity. This chapter is comprised of two main sections.

The first section presents the findings from the positioning model in the participants' prostate cancer stories to cover the stages of their cancer experience (pre-diagnosis, diagnosis period, treatment, and post-treatment). It demonstrates the interactions of the aspect of the participants' hegemonic, Arabic, and Islamic masculinities with their illness experiences. These interactions are presented in four subsections. The first three subsections show the interactions in the pre-diagnosis experience, being diagnosed with cancer, and treatment and post-treatment experience. The fourth subsection demonstrates the influence of the cancer experience on the participants' roles according to their positions in their stories as the man of the house, which is where their Arabic and Islamic masculinities are mainly exhibited.

The second section discusses the integration of the findings presented in the first section with Connell's gender relations model to clarify how this illness experience would affect the gender identity of these men.

## **6.2 Section one: masculinity and the prostate cancer experience**

### **6.2.1 Pre-diagnosis experience: less concern and tolerating the symptoms**

The interactions between the participants' masculinity and their prostate cancer experiences begin with their pre-diagnosis experiences, especially in their responses to pre-diagnosis symptoms and the reluctance to seek medical help. This subsection demonstrates these interactions through the way the participants positioned themselves in their experiences with their pre-diagnosis symptoms and the prostate cancer diagnostic tests. Most of the participants highlighted symptoms such as pain, urological symptoms, and sexual problems in their stories, before their diagnosis with the cancer. These symptoms caused them difficulties such as urinary frequency, urinary urgency, or discomfort during intercourse. Some of those men such as Participants 2, 8, 10, and 13 had experienced these symptoms and difficulties for a long period of time, or they waited until the symptoms became incapacitating before they sought medical help. This point is illustrated in the following examples:

When I went toilet to pee, I peed a drop by drop. I was in urgent [to urinate] but I could not pee. I just peed a drop by drop. I was like that for a month or less. (Participant 2)

It [urine stream] was intermittent...Then, I started having pain from the pelvis to my back...The pain in my back and pelvis increased, which made me see a urologist. (Participant 8)

Participant 2 had symptoms for a month, which suggests that he perhaps was not concerned about these symptoms too much and did not seek medical help until the symptoms had persisted for a considerable period of time. Likewise, Participant 8 did not take any action for his

urination problem until he started feeling pain; the pain was the red flag that convinced him to see a urologist. As noted by Chambers et al. (2018), King-Okoye et al. (2017) and Taghipour (2009) men from different backgrounds are often reluctant to seek medical help, as they try to emulate strength, an important aspect of hegemonic masculinity. Hegemonic masculinity (as described in section three of Chapter 2) is created in the power relations dimension and is mainly presented by strength and dominance. Thus, these studies refer to an aspect of hegemonic masculinity where the dominant discourse is presented as one that is predominantly concerned with ‘strength and power’. It can be argued therefore that Participant 2 and Participant 8 are more likely to position themselves like other men in this dominant discourse. That is, they performed and presented an aspect of their hegemonic masculinity (strength) by minimising or disregarding illness symptoms or being reluctant to seek medical help.

Other possible expressions of strength were captured in their tendency to tolerate, rather than to question, their pre-diagnosis symptoms and their difficulties. Participant 1, as an example, touched upon this issue in his story when he visited a urologist:

The enzyme [PSA level] was high. I went to a urologist and he asked me if I had any problems with urine. I said [to him] it was fine. I mean I tolerated [the discomfort or difficulties] from urine intermittency and the burning sensation. (Participant 1)

This man claimed that his urination problems were “fine” to illustrate that these problems did not concern him. At the same time, he used the word “tolerate” to bring to the foreground the insignificance of the symptoms since they were bearable. Here, he is possibly positioning himself as strong by his ability to tolerate the symptoms and by not considering them as a problem, which is also, it may be argued, another way of showing strength and toughness, aspects that are commonly associated with masculinity.

Illustrations of the participants’ perceived masculinity continued in their experiences with the prostate cancer diagnostic tests. A few of them, such as Participants 5, 7, and 9 mentioned in their stories that they experienced pain during and after their biopsy procedure. How they positioned themselves in that experience provided insights into the interactions between their masculinity and the procedure. For instance, this seemed more obvious in Participant 5’s case when he recounted his experience with this procedure:

Of course, the biopsy was really annoying. I mean it was *terrible*. There was blood after the biopsy. Any man will be irritated from this test. It [the procedure] was *painful* because he [the specialist] took 5-6 samples from a particular or same area. Truly, it was really hard...I tolerated that pain during the procedure...When I went home, a large

amount of blood came out [from rectum]...I took Voltaren for the pain and slept.  
(Participant 5)

This participant described how the biopsy procedure was painful, and, in a reference to masculinity in general, how ‘any man’ would be disturbed by it. He also indicated that even though the procedure was hard, he “tolerated” the pain during the procedure and until he reached home. This suggests that he was highlighting his ability to tolerate the pain as a kind of masculine stoicism. As mentioned by Daibes (2011), Ettridge et al. (2018), and Oliffe (2004), stoicism, like hiding emotions and tolerating pain, is a signifier of hegemonic masculinity. In this case, the participant perhaps positioned himself in this experience with the biopsy procedure in the form of stoicism, i.e., an aspect of his masculinity but at the same time, it indicates that the pain from this experience may cause a threat to this aspect of masculinity by testing the ability to tolerate that pain.

To conclude, the results in this subsection indicate that there were two main interactions between some of the participants’ perspectives of (hegemonic) masculinity and their pre-diagnosis experiences. Firstly, their (hegemonic) masculinity of those men could have an influence on their responses to their pre-diagnosis symptoms and on the reluctance to seek medical help. Secondly, the challenges they experienced in the pre-diagnosis period including the pain associated with the biopsy procedure were a test to this aspect of masculinity in terms of threatening their stoicism and examining their ability to tolerate them.

### **6.2.2 Being diagnosed with cancer: appearing strong or weak**

The interactions between the prostate cancer experience and the participants’ masculinity continued during their diagnosis with the cancer. This subsection shows the influence of being diagnosed with prostate cancer on the aspects of participants’ hegemonic, Arabic and Islamic masculinities. This influence was noticed in how the participants positioned themselves, which was initially manifested through their responses to their diagnosis, and later in their stories in reaction to their cancer. This discourse tended to reveal elements that highlighted the dominant discourse ‘masculinity presents in strength and power’. However, in Chapter 4, the participants were divided into two groups. The first group was the participants who claimed that they were not worried or afraid of their diagnosis with cancer. In contrast, the second group were participants who were afraid or concerned about having cancer. These responses, therefore, could indicate how the participants generally positioned themselves as strong or weak in response to their cancer, which is again where aspects of masculinity were demonstrated by either showing strength or by feelings of weakness.

Furthermore, the findings in Chapter 4 presented evidence that most of the participants, and even other individuals in their stories, directly or indirectly linked cancer with death. This linking mainly emerges from the common perception of cancer as a distinct prospect of eventual death, which has also been highlighted in Jordanian, Middle Eastern, and international studies, such as the studies of Ahmad, Dardas, and Ahmad (2015), Daher (2012), Ettridge et al. (2018), and Khalil (2013). Sharing this common perception of cancer among people from different areas and backgrounds features the dominant discourse ‘Cancer means death’. This dominant discourse can also be a discourse that the participants position themselves under. Therefore, how the participants positioned themselves under this discourse would also illustrate the influence of their diagnosis or having cancer on their masculinity. For example, their positioning under this discourse may reflect their bravery in facing cancer (death), which can be an aspect of representing not only Arabic but also the Islamic masculinities according to Aslam (2012).

Regarding the participants’ stories, the diagnosis of prostate cancer was clearly a major event for all of them. However, the participants in the first group indicated that the weight of it was not for themselves, rather, for their families and loved ones. Their common responses were not being afraid or worried about cancer. This could be bravado, but it could also reflect their notions of masculine strength and bravery. Participant 3, for instance, indicated his fearlessness from cancer when he stated: “I was not afraid... I know it is cancer and people are afraid of it”. The same reaction of no fear was also Participant 11’s view:

Everyone [referring to his family] was affected by the news [of his diagnosis with cancer]. They were terrified, except me. I was not. I was not afraid. (Participant 11)

Both men here positioned themselves as being unafraid in facing the news of their diagnosis of cancer, and when comparing with others, such as their families or other people in general, wished to express bravery or strength. Their positioning possibly highlights an aspect of their hegemonic masculinity by showing their strength in the face of severe adversity. Yet at the same time, their positioning also reflects an aspect of their Arabic masculinity, i.e., by showing braveness and courage, especially in facing critical or hard situations. This aspect of masculinity (as noted in section three of Chapter 2) reflects masculine characteristics of the real man, ‘*Rajul*’ in Arabic Middle Eastern culture. It is therefore argued that Participant 3 and Participant 11 resisted the influence of the diagnosis of cancer on an aspect of their hegemonic and Arabic masculinities by presenting their strength and bravery in not displaying a sense of worry or fear of cancer.

Moreover, some of the participants in the same group revealed their strong faith when they talked about their diagnosis moment. According to them, faith was the source of their response to not being afraid of the diagnosis of cancer, thus making them feel stronger. This is clear in the following:

I am a believer. Praise to Allah that cancer did not affect me...Also, I am an old man. I mean I have never been afraid of death. If death is my destiny, let it be. (Participant 8)

I did not make it a big deal...I was not afraid...Praise to Allah. Strong faith manages this situation [having cancer]...Again, I am not young to be afraid. I mean I am 70 ((laughing)). It is normal to die at this age or around it. (Participant 14)

Both men showed that they were not very concerned about their diagnosis with cancer by stating: “cancer did not affect me” or “I did not make it a big deal”. At the same time, they highlighted their age and their Islamic faith related to death and destiny to present themselves as old Muslim men who were near death with or without cancer. As indicated in Chapter 4, this highlighting could present their acceptance of their cancer as their destiny, even if that destiny leads to death. However, linking their cancer with death also refers to the dominant discourse ‘cancer means death’. In this case, those two men are possibly positioning themselves under this dominant discourse as mature men with strong faith who face cancer (death) without fear. Their positioning suggests their braveness of facing cancer (death), which can be an aspect of representing Arabic and Islamic masculinities according to Aslam (2012). Hence, those two men, like Participant 3 and Participant 11, possibly contained the impact of their diagnosis of cancer on their Arabic and Islamic masculinities by facing it with braveness and without a sense of fear.

Furthermore, with the first group, some of the men viewed their experience with prostate cancer as a battle. It was obvious in many cases among this group as they used words in their narrative such as “defeat”, “resist”, “surrender”, and “die upright”. For example, Participant 1 used the word “defeat” when he stated: “It [cancer] did not defeat me. *No*, I controlled it”. Participant 11, as another example, used the same word when he talked about his cancer: “I cannot imagine that disease will defeat me. I resist it”.

Both Participant 1 and Participant 11 believed that their cancer did not or would not defeat them. They positioned themselves as stronger than their cancer and believed that they had the ability to control and resist it. Interestingly, they both mentioned a quote from Arabic poetry about fighting and facing death while they were recounting their experiences with cancer. According to Mawassi (2016), the quote is by Ibn Nabatah Al Saadi and it says:

وَمَنْ لَمْ يَمُتْ بِالسَّيْفِ مَاتَ بِغَيْرِهِ      تَعَدَّدَتِ الْأَسْبَابُ وَالْمَوْتُ وَاحِدٌ

In English, this quote translates to: “Who does not die by a sword, dies without it. Causes may vary but death is one”. In the context of these men’s cancer stories, the quote has two possible interpretations. Firstly, cancer is simply as any other cause that a person may die from it. Secondly, dying by a sword (an indication of fighting cancer) is more noble way to die. In this context, both men perhaps meant the second interpretation of the quote. Hence, they could demonstrate the aspect of their Arabic masculinity by stressing their fight against cancer and their ability to defeat it.

Similar to Participants 1 and 11, Participants 10 and 12 also considered their experiences with cancer as a battle. They said they were not scared of facing cancer -or death- and they were not going to easily surrender:

I was not worried or afraid of cancer or death...People may have a fear of cancer. The word ‘cancer’ arouses fear. But I am not afraid because I can defeat it...I am not a kind of person who easily surrenders. (Participant 10)

I am a man of belief...I am over seventy. It does not matter if I die tomorrow...I was not afraid from this disease. I am not a kid or young...In the end, I want to die upright. I want to die this way. (Participant 12)

Participant 10 outlined the common fear among people, that cancer often causes death. His repetition on saying “I am not afraid” was emphasising that cancer, which people are usually afraid of, did not cause him fear. He therefore wished to appear strong in facing cancer (death) without fear, comparing himself with other people who he believed would be fearful of it. The same was evident in Participant 12’s responses when he indicated his fearlessness from his cancer or death as an old man of faith illustrating his strength in facing cancer. Meanwhile, both continued expressing their willingness to keep fighting cancer without any intention to surrender. Participant 10 directly stated this when he defined himself as a person who is unlikely to surrender, while Participant 12 indirectly indicated that as he wanted to die with dignity “upright”. As discussed in subsection 2.4.3 of Chapter 2, being brave and steadfast in a battlefield is also considered a major aspect of Arabic and Islamic masculinities. Hence, the two participants’ positionings may be said to represent their Arabic and Islamic masculinity through their ability and persistence of fighting against cancer. This suggests again how those two men, perhaps like others in the same group, maintained their masculinity when impacted by a diagnosis of cancer.

In contrast, the second group of the participants were significantly affected by their diagnosis of prostate cancer. Their responses at the time of the diagnosis included feelings of worry and

fear: “I was afraid... *What! Cancer.* I was terrified” (Participant 2), “I was terrified. I said to myself: “it is over. My life is over”” (Participant 4), “I was scared...A person gets scared and goosebumps of it” (Participant 6), “This disease would kill me” (Participant 7), and “This is an *evil disease...* You know it is cancer” (Participant 9). Based on their reactions, those men possibly perceived prostate cancer as being very serious since they were scared by it as if it would end their lives. This, as a result, perhaps indicates that the diagnosis of prostate cancer, instead of being a way of promoting their masculinity, could threaten their masculinity by causing fear and uncertainty in their lives.

However, these participants in this group also received support from their wives, families, friends, and healthcare professionals after their diagnosis with cancer. That combined support, rather than an inner belief in their own masculine and/or Islamic strengths, gave them courage to cope and accept their illness. This was obvious in the experience of Participant 4 and Participant 9 when they mentioned the psychological and religious support from their wives:

My wife consoled and felt for me. She said to me: “life is not over. Any human is vulnerable [to get sick or get cancer]. He will not live forever. What Allah has written; it happens”. I swear by Allah that I have taken her words as a rule. He who has strong faith in Allah, will not be afraid of death or cancer. (Participant 4)

My wife is a strong believer. She has tightened my waist [an Islamic metaphor of support]. She keeps telling me: “Not to be afraid. This is from our Lord”...I am not afraid of death...You should be patient when you have illness. I am patient and the patient gets rewards [from Allah]. (Participant 9)

Here it is seen that the two participants’ wives helped their husbands in coping and accepting their illness. The wives’ support helped the two men feel stronger by reducing their fear of cancer and strengthening their Islamic faith of destiny. Then again, the two men also stressed the importance of faith in facing death, namely that a believer should not be afraid of it. These men also linked their cancer with death like others in the first group, which refers to the dominant discourse ‘cancer means death’. They possibly defined themselves under this dominant discourse as a person who faces death, but with a strong faith. This notion is clear in Participant 9’s quotation when he says: “I am not afraid of death...I am patient”.

As discussed in Chapter 2 and noted earlier in this chapter, facing death without fear and being patient to the hardships of life are signifiers of Arabic and Islamic masculinities. Thus, it would seem that Participant 9, possibly Participant 4 too, wanted to limit the influence of cancer on aspects of their Arabic and Islamic masculinities after the diagnosis by directly noting their mental stoicism, and sometimes, their strong faith in facing it. The general theme of masculine

stoicism was reflected in other stories, for instance, Participant 7 showed his strength after the diagnosis by deciding to face his cancer and not to give up:

Finally, I psychologically accepted the [illness] situation. I mean I did not want to give up. I said to myself if I give up, my family would be destroyed. No, I did not give up. (Participant 7)

This participant's decision not to give up was an illustration of how he faced the cancer and was fighting back. As previously maintained (as in Participant 10's and 12's cases), fighting back and not surrendering to cancer can be a sign of showing strength and Arabic masculinity against it. After the diagnosis, this participant perhaps attempted to reduce the impact of cancer on his masculinity by fighting back and not giving up, although at the same time, his decision was also based on his concerns about his family. Yet here too, he might want to protect his family from the consequences of his illness, which itself reflects his perceived role as a father, the protector of the family. His diagnosis with cancer could also challenge this role, where another aspect of his Arabic and Islamic masculinity would be exhibited (see more about this masculine role in the fourth subsection of this chapter).

Some men in the second group tried to resist the influence of cancer on their masculinity after the diagnosis by showing their strength in facing it and fighting back. Nevertheless, those men still feared cancer and its recurrence after they completed their treatments. This was obvious in their responses when they revealed their current illness situation: "I cannot rest assured with this disease. It may come back" (Participant 2), "It is not easy, and a person is afraid if it metastasizes" (Participant 5), and "There is still fear. This disease is evil...It may come back again after 4-5 years" (Participant 9). It was more noticeable in Participant 7 since he went through cancer treatment at different times over his six years' experience with cancer:

Cancer is not easy. I may deal with it. *Alright*. I wish I could defeat it, but I am *weak*. I faced it with the courage. But I am *still weak*. I am a human and I do have feelings. (Participant 7)

This participant, and others in the second group, maintain that he faced and dealt with cancer with courage, thus indicating that he tried to contain the impact of cancer with (masculine) courage. But in the meantime, his responses of fear and worry about his current illness possibly reflected his repositioning of cancer as a strong opponent. The responses demonstrated that he considered that the cancer would not be easily defeated if it recurred. Difficulty in defeating cancer and the fear of its recurrence could therefore develop a sense of weakness, which would threaten the individual's sense of masculinity. It was obvious in Participant 7's quotation when he emphasised his sense of weakness. This suggests that the impact of cancer on at least some

of the participants' beliefs in their own masculinity did not stop at the diagnostic moment but continued even after completing treatment.

Looking from a different angle, being diagnosed with prostate cancer had another indirect influence on the participants' masculinity by its impact on how other people positioned them in their cancer stories. This is related to the various ways that most of the participants explained how their diagnosis with cancer would, or had, changed the way in which other people looked at or treated them. Participant 5, as an example, touched upon this issue when he explained why he hid his cancer diagnosis from other people:

The diagnosis of this illness is a weakness...I cannot accept that someone sees me as weak. My personality is *strong*. I mean, I was a general manager with a strong personality, who had never regretted his decisions. I still have this personality. (Participant 5)

This man described his diagnosis with prostate cancer as a weakness which would result in people viewing him as weak. In turn, he rejected this sense of weakness by saying: "I cannot accept that someone sees me as weak". His rejection was in part based on his strong personality and the authority position (general manager) that he used to be in, and it may also be argued that his strong personality and authority position is also a reflection of hegemonic masculinity. As discussed in Section three, Chapter 2, this masculinity in any society or culture, including the Middle Eastern, can be presented as a type of power, i.e., by appearing and attempting to be strong in front of people, especially when in any position of authority. Subsequently, this man verified his hegemonic masculinity through his strong personality and position as a manager, and it was this that caused him difficulty being seen as weak. This explains how his diagnosis with cancer created a challenge to his hegemonic masculinity.

Another example of a challenge to hegemonic masculinity was outlined by Participant 4 when he talked about how his colleagues at work sympathised with him and tried to reduce his workload once they knew about his diagnosis with cancer:

I felt my colleagues started looking at me with pity or sympathy. They wanted to reduce my workload. I totally refused that...I did not like their way of treating me. Since diagnosis, my control has increased over them...I want to prove my masculinity. (Participant 4)

The participant outlined how his diagnosis with cancer had an influence on other people viewing him as a cancer patient who needed sympathy or special treatment. He interpreted colleagues' sympathy and their special treatment toward him as a weakness, which he refused. Similarly, to Participant 5, he presented his hegemonic masculinity in his authority position at

work by increasing his control over his employees to prove that he was still strong. This indicates how people's sympathy towards him due to his diagnosis with cancer translated to being seen as weakness, which consequently could conflict with his power position at work, the position where his hegemonic masculinity was of considerable importance to him.

In Chapter 4 and Chapter 5, I highlighted that the participants' families became involved and a part of the cancer experience of their male relative. I also indicated that this involvement had an influence on the nature of the relationships between the participant and their families. As a result, some of the participants mentioned that they received sympathy and special treatment from their families during and after their diagnosis with prostate cancer. However, this sympathy was not necessarily wanted or fully appreciated by the participant and led some of the men to think they were viewed as weak. Participant 12 provides a salient example:

My family still consider me as a patient. They sympathise with me but not to a level of pity...I still have control over the house and the situation is stable. My sons and daughters still listen to my words [obey him]...I still treat them in the same way, so they do not feel that I have changed with this disease...I have not asked them to drive me there [the hospital]...I am not weak, tired, or sick. No, I can [do things independently] until now. (Participant 12)

This man stated that he received sympathy from his family, which was mainly because of his diagnosis of cancer. Their sympathy referred to their feelings that cancer had an impact on their father. In turn, he tried different strategies to convince them that he was not affected by cancer, such as treating them in the same way as before his cancer, showing his ability to maintain control over the house, and doing daily activities without assistance. In Arabic society, all these strategies may be considered as a way for him to prove his strength and hegemonic masculinity as he positioned himself in an authority position at the head of the family. This was made quite clear when he highlighted that he still had control of the house and his family were still obeying them. Clearly in this instance, his diagnosis of prostate cancer could threaten his hegemonic masculinity in his position as head of the family by presenting him as weak in front of them. However, this man tried to limit the threat that was presented by their sympathy by asserting that he was still in control and demonstrating his independence through continuing his daily activities without assistance. Similar examples are also seen in the cases of Participant 1 and Participant 14:

They [referring to his family] cannot believe that I do not care about this disease and it does not affect me. They treat me as a patient. They ask me to rest and stay home. I refuse that...Some people get surprised. How come that I am diagnosed with cancer and I still come and go ((laughing)). (Participant 1)

They [referring to his family] still think cancer affects me. They try to help me with work, but I reject their help. They make me feel weak. No, I am good. (Participant 14)

The two participants above mentioned how their diagnosis with prostate cancer changed the way their families treated them. Their families viewed them as sick men who needed to rest or required assistance. This position was rejected by both participants, clear in their comments: “I refuse that”, and “I reject their help”. From one perspective, both men, like Participant 12, most likely wanted to show to their families that they remained head of the family, were still strong and were not affected by their illness. From another perspective, they possibly did that as a kind of protection to convince their families they were still okay, so their families would not be stressed or worried about their sick fathers. Once again, this intimates how prostate cancer could challenge those men’s masculinity in their positions as the head and the protector of the family, while they were trying to resist the challenge by showing strength and independence to their families. More about the ‘protection role’ will be discussed later in the fourth subsection of this chapter.

For some participants, however, the effect of the family’s sympathy weighed heavily on them, as in the case of Participant 7. He explained that his family’s sympathy caused him psychological pain:

They still look at me with a sympathetic look, especially from my daughters. They tear when they look at me. *It kills me*. It is like RPG [a rocket] enters my chest. They think that their father is over, and cancer means death...I always keep the smile on my face in front of my family. I do not want to reflect the sorrow [pain] I feel at them...I have been suffering for 6 years and everyone says that my spirits are high and very impressive- but I am weak. (Participant 7)

Like the three previous examples, the family’s sympathy is in relation to his prostate cancer, but in this instance their sympathy made their sick father feel that he might not only die, but would appear weak to his family, which may explain his comment that their sympathy was as painful as a rocket in the chest. Paradoxically, he admitted that he was weak from his illness, but at the same time, was hiding his feelings of pain, sorrow, and weakness in front of his family and in front of others. He, like the men in the previous three examples, wanted to reduce sympathy to convince others that he was still strong. Hiding his weakness was effective for some people; they were impressed with his high spirits in facing his disease. However, it did not work as well with his family since they still looked at him with sympathy and deep concern, impacting his perception of his masculinity.

To summarise, the results in this subsection show more interactions between the prostate cancer experience and the participants' masculinity. The main interaction was seen at the moment of diagnosis by causing the sense of fear and uncertainty about their lives. The sense of fear and uncertainty were associated with the common perception of cancer as a debilitating disease leading to death, and often with losing hope. It may therefore be maintained that the sense of uncertainty and fear of cancer or death had an influence on the aspects of participants' hegemonic Arabic and Islamic masculinities in terms of strength and weakness. Some of them, like the participants in the first group, found a way to contain this influence, such as showing no fear, being unconcerned about having cancer, or showing their bravery, strong faith, and patience in facing it. Others resisted its influence by fighting back and attempting to remain strong during the trajectory of their illness. However, its impact on their masculinity continued after their treatments as some men still had the worry of cancer recurrence, and for some, further debilitating consequences. It follows that for some participants at least, this anxiety and unease raised a sense of weakness, fear, and uncertainty for them resulting in a continued threat to their masculinity.

Overall, sympathy from family and others about the cancer impacted the participants' sense of masculinity in different ways. The sympathy and the special treatment could also come from the common perception of cancer as death and losing hope. Receiving this sympathy and the special treatment as a cancer patient possibly developed in those men a feeling that they were seen as weak in front of people, which could interfere with their hegemonic masculinity. As noted in the examples earlier, being seen as weak in front of others would affect their authority and hegemonic relationships within their Jordanian Islamic society, the positions where this masculinity was mainly presented. Participants 4 and 5 were examples of how diagnosis with prostate cancer presented them as weak in front of people and challenged their position and strong personalities as managers. Likewise, Participants 1, 7, 12, and 14 gave examples of how sympathy and special treatment from their families had a negative impact on their perception of their position as a father and the head of the house. In turn, those men refused to be seen as weak or affected by their cancer, which became a challenge because in private they admitted to feelings of weakness from the illness. So, they tried again to resist the influence of prostate cancer on their masculinity by presenting their strength in front of others, either by showing their ability to maintain their authority positions or showing their independence in activities of daily life.

### 6.2.3 Masculinity and treatment/post-treatment experiences

The previous subsection has shown potential influences of a cancer diagnosis on the participants' masculinity. This subsection demonstrates how the prostate cancer treatment and post-treatment experiences also had an impact on those men's masculinity. It begins with their experiences of radiotherapy. As discussed in the findings of Chapter 4 and Chapter 5, most men spoke of how the radiotherapy was very stressful and tiring because of the procedures involved. They were required to have a full bladder before each session and to hold it until the session finished. This took place daily except weekends for on average, two months. It was a big challenge to most of the participants, testing their strength and their ability to control and hold their full bladders. However, six of the men mentioned that they were unable to hold on and were incontinent during the radiation sessions, with consequences that they found to be most disturbing. Participants 6 and 8 are examples of this:

I could hardly hold myself during the radiation sessions. One-time while I was on the [radiation machine] table, I wet myself and filled the room with urine. I usually could hold on, but I *could not* that time...I *suffered*. I could not believe it when I finished my radiotherapy. (Participant 6)

It [the procedure] was a *big, big, big problem*...If there was a delay for any reason, I would wet myself. It would be a mess...It [micturition incidents during radiation session] happened to me twice. I tried to hold myself, *but I could not. I could not*...I asked: "Oh, Allah! when will the radiation be over?" (Participant 8)

The two men above outlined how the radiotherapy sessions were exceedingly difficult in terms of their ability to hold their full bladder for the required time. Despite the difficulty, they both highlighted that they were able to retain their urine in most of the sessions. They emphasised how hard they tried: "I usually could hold on, but I *could not* that time" and "I tried to hold myself, *but I could not. I could not*". Essentially, they both tried to communicate a notion of strength by control over their bladders. However, failing once or twice could cause them a sense of powerlessness or weakness, of losing control over their bodies. They possibly felt themselves to be weak when the micturition incidents happened suggesting that the radiotherapy procedure may have caused a challenge to the men's masculinity, and possibly to others who had the same incidents, by testing their strength and ability to hold a full bladder and maintain control over their bodies.

The radiotherapy procedure was for a specific period of time, which would indicate that its effect on masculinity may also be limited to that period. Yet, as previously indicated, the complications of this treatment had physical and psychosocial impacts on most of the participants, which (as more fully discussed in Chapter 5) persisted in some instances after

completion of the treatment. For example, two-thirds of the participants had urinary and bowel problems as side effects of their radiotherapy. A few of the participants suffered from these problems, especially incontinence and inability to hold their bladders for long, during and after completing the treatment. This is evident in Participant 7's and 15's story:

Now, I can control my bowels but not on urine [bladder]. I cannot hold it [bladder/urine] for long...If I want to visit my brother, for example, I will keep asking for the toilet 4-5 times in an hour. The same thing is when I am in a meeting with men...I am 70 years old. I frequently use the toilet while I am sitting with other old men...It is *painful*. I feel I am gradually worn down. (Participant 7)

*Why I was like that?* I mean losing control of my urine and bowels. *It annoyed me a lot.* One day, it [loss control of bowels] happened while I was eating in a restaurant. I left the restaurant. It was a very annoying and disgusting experience...I now can control [the bowels], but not urine [the bladder]. Sometimes, I cannot hold it while I am going to the toilet. It mainly happens at home, and it still annoys me. (Participant 15)

The incontinence incidents and inability to hold the bladder for long clearly caused embarrassment and psychological pain especially when it happened in public. These complications could develop a feeling of powerlessness and weakness in these men, since they still had no control of their bodies. These complications appeared to disrupt their self-image as a respected elder. But looking from the aspect of masculine strength, these complications may make these men position themselves as appearing weak in front of others. As a result, feeling powerless and appearing weak due to these radiotherapy complications could interfere with their (hegemonic) position in private and public society, thereby becoming a threat to their masculinity.

Sexual dysfunction was another complication from the radiotherapy that interacted with the participants' perceptions of their masculinity. All participants mentioned in their stories having erectile dysfunction, aggravated by having hormonal cancer treatment. As outlined in Chapter 5, the experiences of sexual dysfunction were varied amongst participants. Some of them were significantly affected from it, while others suggested that they had coped and adapted to it. Those participants who were significantly affected by their sexual dysfunction, either directly or indirectly, indicated its influence on their sense of masculinity, evident in these extracts from the data provided by Participant 2 and Participant 7:

I used to have sex once or twice a week. I stopped having intercourse once I started taking the hormonal injections with radiotherapy...I had tried many times to sleep with her [an expression of having sex], but it [penis] did not stand up [no erection]...I *despised myself*. I was entirely affected. I wanted to be like any man who has normal sex with his wife...When men, who I know, asked me about my sexual ability, I told them it was normal. But it was not. (Participant 2)

We used to have sex once or twice a week and suddenly I found myself [a long silent interval] *nothing*...The most thing that would kill a man is being diagnosed with prostate cancer and being [sexually] away from his wife. A man can bear anything except losing his manhood. It is hard, especially when his wife looks at him. (Participant 7)

Both men addressed how their sexual dysfunction had a strong impact on their sexual lives and on their sense of being a man. Its influence on their sense of being a man also came from their perception of how others had, or would, look at them as a man. For instance, Participant 7 referred to himself and his sexual dysfunction as a man who lost his manhood (masculinity), which consequently he believed, had an impact on the way his wife regarded him. Likewise, Participant 2 indirectly pointed out that his sexual dysfunction made him feel different, not like other normal men. He hid his sexual problem from other men, who had asked him about it. Hiding his sexual dysfunction was most likely from his fear of embarrassment and of being regarded as less than a man. In both cases, these two men linked their sexual ability, or perhaps potency in this context, with their sense of being a man. As shown in subsection 2.4.3 in Chapter 2, potency is commonly considered as a symbol and a part of masculinity among men from different cultures, including Jordanians. This raises the dominant discourse of ‘potency is a part of masculinity’. Consequently, the two men with sexual dysfunction believed they were positioned as less masculine under this dominant discourse and in the eyes of others. This indicates that the sexual dysfunction (impotency) for those two men was a threat to their masculinity.

Participant 4 and Participant 6 had similar experiences. Both men were also significantly affected by their sexual dysfunction:

((With an angry tone)) I have not had sex for 2 years ((dusting his hand)) [an expression of having nothing]...I will be ashamed if I have intercourse with my wife and I end up *with failing*...*I am shy* to ask or tell them [doctors] that I have not had sex for 2 years. He [his doctor] is always with his assistants, who are females. I *cannot ask*. I blush. (Participant 4)

I am deprived of sex...I still see myself as young, not an old man. Even though I am over sixty, there is a sexual desire that needs to be satisfied. I do feel for my wife. Sex is not a problem for her, but it is a problem for me. It lowers your prestige, your masculinity...*I cannot do anything*...I have not had a chance to talk with my doctor in a presence of females. *I could not talk or ask him*...Till now, my sexual ability is completely non-existent. (Participant 6)

Both men expressed their frustration and distress from their sexual dysfunction because sexual activity was important to them, while they could not find a solution to get it back. In the case of Participant 4, he avoided having intercourse with his wife or discussing his sexual issue with

his doctor in the presence of females. He clarified that his sexual dysfunction made him feel ashamed and embarrassed in front of females. Similarly, Participant 6 admitted that he was unable to discuss this issue with his doctor in the presence of a female as raising the issue in front of females would cause him embarrassment, shame or possibly the feeling of being less masculine. Their feeling of shame or embarrassment from sexual dysfunction is common in Jordanian society, and most likely the same in other Middle Eastern Islamic societies since sexual issues are considered an offensive topic to be discussed in front of a female (see subsection 2.3.2 in Chapter 2). In addition to this, Participant 6 presented himself as a young man to express how important the potency was to him since he still had sexual desire. He also directly stated that having a sexual dysfunction lowers a man's masculinity. Here, as in the other examples, his linking of sexual ability with masculinity refers to the dominant discourse of 'potency is a part of masculinity'. This outlines that sexual dysfunction could also have an impact on the masculinity of Participants 4 and 6, as in Participant 2's and 7's cases.

Yet unlike the four men's experiences, many other participants accepted and coped with their sexual dysfunction. The data provided by Participants 3 and 5 are examples of this:

I am 78 years old. It is over ((laughing)). My wife is in her seventies too. The sexual relationship is not an issue to her ((laughing)). She accepted the [new sexual] situation. Her relationship and treatment for me are still the same. So, I am okay. (Participant 3)

I have accepted it [the sexual situation] as a reality. If a man gets it [cancer or sexual problems] at the age of thirty, it will cause a big relapse to himself and to his personality. He is still in the beginning of his life. He wants to get married, to have kids, and to have sex...But for me, I am in my sixties. I am an old man, and this is my limit. I mean I am retired from work and sex ((laughing)). (Participant 5)

The two participants above highlighted their age, most likely to illustrate the notion that their sexual function became less important with age. This was clear in Participant 3's quotation when he mentioned his age, the age that he perceived that having sexual intercourse would not exist: "I am 78 years old. It is over". Participant 5 also referred to himself an old man who had retired from sex, unlike Participant 6 above, who considered himself a young man, even though they both were in their sixties. Participant 5 continued explaining that his story with sexual dysfunction would be different if he experienced it at a younger age. This again relates to the common discourse 'potency is a part of masculinity', where Participants 3, 5 and other men in this study have viewed themselves as elderly men who would normally have less sexual desire or performance regardless of cancer diagnosis. Their positioning as elderly men would indicate that the dominant discourse 'potency is a part of masculinity' might generally be considered

inapplicable at their age. This suggests that the influence of the sexual dysfunction on those men's masculinity was limited.

Besides sexual dysfunction, the participants experienced other side effects from their hormonal cancer treatment, including penis shrinkage, breast development and hot flushes. Their reactions to the experience with these hormonal side effects and body changes varied from annoyance, discomfort, adaptation, and laughter. The side effects could be quite disturbing for some participants, in one instance Participant 10 referred to one of these physical changes as 'feminisation' of his body:

In fact, my testes have shrunk. They become small as a side effect of the hormone [therapy]...Of course, there is hot flushes like a woman in menopause. It comes even in winter...I know it is from the hormone [therapy or injections]. So, I understand the situation. (Participant 10)

This man stated that his bodily changes from the hormonal therapy would not be dissimilar to those experienced by a woman during menopause. At this point, the feminisation of his body due to the hormonal therapy might not have an interaction with his masculinity since he considered it as a direct result from the treatment.

In contrast, Participant 6 was severely disturbed by his experience with hot flushes and the dizziness caused by his hormonal treatment:

Sweating, hot flushes come 10-11 times day and night, in summer or winter...The sweating problem *kills* [severely annoys] me. [It happens] even in people's houses. I keep wiping [the sweating]. One-time while I was walking in a shopping mall, I started sweating. I felt tired and dizzy. People came for help and they started giving me tissues...I was entirely *disturbed. I felt weak*. I am trying to overcome this feeling. I try to hide it from people to avoid their sympathy and their pity look. (Participant 6)

This participant indicated how hot flushes significantly bothered him since it was happening to him many times during the day. This was the same as other men in the study, i.e., Participants 2 and 4. Participant 6 however, sees his excessive sweating from the hot flushes as causing him embarrassment and felt it made people sympathise with him since it happened to him in public and in people's houses. Consequently, the social embarrassment and people's sympathy towards him made him feel weak, which was highlighted in the quotation: "I was entirely *disturbed. I felt weak*". This man described himself here as weak, but at the same time, he tried to appear strong in front of people to avoid their pity or impression of weakness. As mentioned earlier in this section, the sense of weakness or appearing weak in front of people interferes with the sense of (hegemonic) masculinity. This suggests that hot flushes had an indirect impact on this man's masculinity by causing him unease when people showed sympathy towards him,

while at the same time worrying that his sense of weakness in front of others would diminish him as a man.

In all, the results in this subsection demonstrate further interactions between the participants' masculinity with their treatment and post-treatment experiences. The main interaction was observed from the challenges of the treatment and post-treatment experience on the participants' ability to remain strong and steadfast through their experiences with cancer. The radiotherapy procedure and the incidents of incontinence were obvious challenges to those men's strength and their appearance as strong in front of others. Most men faced all these challenges or tried to prove to others including me, as the audience, that they remained strong, which possibly was just 'bravado' or an indication of their resistance of the influence of these challenges on their masculinity. But the significance of these challenges, besides the cancer, on some of them and their lives was stronger than their resistance that affected and kept their masculinity under threat through the cancer experience.

The results also presented the impact of these participants' experiences on the signifiers of masculinity in their male bodies. The radiotherapy and hormonal therapy caused changes, such as impotency, hot flushes, and other distressing symptoms. For some participants, their male body had an obviously strong connection with their sense of masculinity. Consequently, their experience of bodily changes, especially erectile dysfunction, provided a significant threat to their sense of masculinity. For other participants, these physical changes were not considered as a threat since they reframed the signifiers of their masculinity. Their reframing was clear by accepting these changes as a natural process of aging and a consequence of the illness.

#### **6.2.4 Since the family were involved: expected roles as 'the man of the house'**

This subsection presents more interactions between the prostate cancer experience with the participants' masculinity through their roles as Jordanian Muslim men. The participants presented themselves as husbands and fathers in different parts of their stories with prostate cancer. Through these portrayals, they outlined their roles as protectors and providers of the family, where a form of their Arabic and Islamic masculinities would be exhibited (see subsection 2.4.3 in Chapter 2). Therefore, the influence of the prostate cancer experience on the participants' ability to maintain their roles as protector and provider for the family would impact on their masculinity as Jordanian Muslim men.

Revisiting the participants' stories, their position as a father within the Jordanian family was apparent when they talked about their diagnoses with cancer. As noted in Chapter 4, their

diagnoses with this illness were major life events, which would be expected to cause distress and emotional instability for their families. Three of the participants hid the diagnosis from their families because they were worried about how they would react if they knew about their 'sick father'. This was clear for Participant 5 and Participant 6:

I did not spread the news. Even my sons, they do not know about my diagnosis. My sons are not old enough. The eldest is 25 years old. I am worried about their worries. If they know that their father is sick, they will be too worried and stressed...My son will think about what will happen next to me and how much time is left for me to live. Their feelings will be disturbed. (Participant 5)

I did not tell my youngest son. I told the eldest one. I did not tell my married daughter, but she knew through her husband. I did not want them to know. I did not want them to get hurt in the first place...Unfortunately, my wife discovered my diagnosis through the stamp of the cancer centre on my medical reports. She was massively affected. I reassured her to increase her spirits...I do not tell my family about my problems. This is my nature. (Participant 6)

From the quotations above, the two participants expressed their concerns about their family reactions if they knew about their diagnosis with cancer. Although Participant 6 told his eldest son about his cancer, he and Participant 5 hid their diagnosis with the disease from their close family members, especially from the daughters and young sons. They explained that hiding the news of their diagnosis was to protect their family from the psychological and emotional effects. Both men position themselves here as protectors of the family, which can be an aspect where they demonstrate their masculinity. So, their diagnosis with the cancer had perhaps tested their role as protector of the family. For Participant 6, his wife knew about his cancer diagnosis, and it was a shock for her. As a result, this man tried again to maintain his protector role through reassuring his wife, even though he himself had concerns.

Like Participant 6, most of the men did the same when their family knew about their cancer. Their families were shocked from the news, which encouraged the participants to try lessening the impact of that distress. Participants 1 and 2 are typical examples:

My sons, daughters, and wife were crying when they knew that I had cancer. I said to them: "Allah puts faith in us. We should be patient to get his rewards. Why are you trying to lower my spirits?". I mean I gave them support. I reminded them about faith to defeat this disease...I asked them: "tighten my waist to tighten yours" [a common Islamic metaphor for support]. (Participant 1)

*What! Cancer.* I was terrified. Anyone would be afraid. My nerves collapsed [an expression of shock]. I said: "I was over"...My wife knew because she was with me. Of course, she was terrified and started crying. I asked her to put trust in Allah. What comes from Allah is always good. (Participant 2)

Both participants positioned themselves as protectors of their families as they felt obliged to support them in this critical time of the diagnosis of cancer. As may well occur within typical Jordanian families, they both used their Islamic faith as a strategy to help their families accept the news and cope with it. However, other men in this study used another strategy to reduce the distress of their diagnosis on their families. For example, Participant 13 and Participant 14 mentioned in their stories that they positively reacted or attempted to keep their spirits high after their diagnosis of cancer to encourage their families to respond in the same way:

I positively reacted when the doctor told me that I had prostate cancer...The same reaction was from my family. I mean I gave them the impression. If I was distressed or became anxious, it would reflect on them. (Participant 13)

I did not make it a big deal. I kept my spirit high in front of my family. They were not affected much when they saw me in good spirits. Of course, their reaction was based on my reaction. (Participant 14)

From the six examples above, the men's support, protection, and reassurance strategies to their families in their diagnosis period would clarify their Arabic and Islamic role as a father and as a husband, the role that should be maintained by them as 'the man of the house'. This suggests that the response to the diagnosis of prostate cancer could influence those men's Arabic and Islamic masculinity in their role as protector of the family. Yet, this interaction continued after the diagnosis period with their treatment and post-treatment experiences.

The previous two subsections of this chapter have presented that the diagnosis with prostate cancer, the treatment and post-treatment experience had changed the way families looked at or treated some of the participants. In response to this, the participants hid their feelings of weakness and tried to show their independence in doing daily activities and to appear strong in front of their families. The participants' responses and behaviours in this way are possibly to prove their strength and demonstrate their hegemonic Arabic masculinity in their position as the head of the family, which has been discussed in the second subsection of this chapter. It is also possible that those men have displayed their strength as a way of protection to convince their families that they were 'okay' and to make their families less worried about them. In this case, the prostate cancer experience could also challenge the participants' masculinity as Jordanian Muslim men by testing their ability to maintain their protector role during their cancer experiences.

Being a provider was another role where the prostate cancer experience could have an interaction in relation to participants' masculinity. Although most of the participants were already retired before their diagnosis with cancer, some of them still had concerns with the

financial impact of their illness on them and on their families. Their financial concern in their stories highlighted the influence of their prostate cancer experiences on their ability to uphold their role as provider for the house. As an example, Participant 4 touched upon this issue when he recounted his diagnosis with cancer:

In the beginning, I was psychologically tired, *very distressed*. It was because my sons were still studying at universities. *Who would pay their tuition fees? Seriously*. All of them were studying in subjects like engineering with high tuition fees. Masculinity is to protect your family, to save them, and to be able to spend money on them...I still work. Thanks to Allah for everything. (Participant 4)

This man expressed how his diagnosis with cancer added more stress on him when he started thinking about the financial consequences of his illness on him and his family. He viewed himself as a protector and provider for his family. He explicitly stated that these roles were part of his perspective of masculinity, that he should maintain the status of ‘the man of the house’. He also pointed out that he was still working even with his disease to illustrate that he was still able to continue with his role as provider. This suggests that his diagnosis with cancer could cause a threat to his masculinity in his role as a provider since this illness would affect his ability to work and would cause a financial burden. However, the threat was most likely limited because he was still working and was able to maintain that role, but this was not entirely the case for some of the other participants.

Similar to Participant 4’s response, Participant 7 was very stressed about his diagnosis with the cancer and the potential financial impact on his family:

How I would [financially] handle my [cancer] treatment. It had a big role to make me feel sorrowful. I mean I was seriously thinking that this disease would kill me. In seconds, I wished I [would] disappear and never existed. It is because I do not want to cause any pain to others. I mean *how could I put a burden to my sons*, who are freshly graduated or still at the beginning of their lives and let them carry the responsibility [of covering the cancer treatment or living expenses]. A father thinks in this way. I mean any father, not only me...Of course, I stopped working...My sons brought me money in a way that did not hurt me...My brother in-law knew that I stopped working; had no income and my sons bore the [financial] burdens. So, he tried to help. (Participant 7)

From the quotation above, this participant highlighted the impact of the diagnosis of cancer on him as the man who used to carry the responsibility and the financial burden for the family’s comfort. At the time of the diagnosis, he began thinking about how he could financially handle his illness and its treatment without causing any burden to his family. He pointed out that this thinking would be the same for any father. Here, he is clearly positioning himself as a father, the protector, and the provider of the house. Focusing here on his role as a provider, he indicated

that he stopped working and now this role became his son's responsibility by saying: "had no income and my sons bore the financial burdens". Losing his job due to his diagnosis with cancer had an impact on his financial independence and his role as a provider of the family, which eventually made his sons take this masculine role and they possibly became the 'new' men of the house. From this aspect, it suggests that the financial consequences of his diagnosis with prostate cancer could create another challenge to this participant's masculinity by making him unable to maintain his role as a provider of the family and passing it on to his sons.

In another example, Participant 15 echoed the experiences of Participant 7. He stopped working, but in his case, this was mainly because of his colorectal complications from his radiotherapy:

Of course, I stopped working...The complications of the treatment keep me home. It annoys me a lot...My wife thinks that a man has to go out and work, but she does not say that...I want to work and to have an income. I try as much as I can, but *I cannot*. It is because of these complications. (Participant 15)

This man expressed how these complications forced him to stay at home and how it limited his ability to work, which consequently could affect his financial independence and his role as a provider of the house. He pointed out that working and being a provider were a man's role when he talked about how a woman (his wife) would think about a man: "a man has to go out and work". This indicates the connection of working and being the main source of income with his sense of masculinity. So, the impact of the prostate cancer experience on his ability to work and to maintain his role as provider could become a threat to his masculine sense as man of the house.

To summarise, the results in this subsection show additional interactions between the other aspects of the participants' Arabic and Islamic masculinities with their experience of prostate cancer. The interactions were evident in their roles as 'man of the house' since their families were included in their experiences with this disease. Most of the participants tried to maintain their role as a protector either through hiding their diagnosis and their weakness from their families, or by showing their strength and independence to convince their families that they were not affected by their cancer. It was a test to those men to keep up with this role throughout the whole experience with the cancer, which eventually became a challenge to their masculinity as man of the house. For some of the participants, there was another challenge on their masculinity from the financial consequences of their prostate cancer experiences on their role as a provider. Those men stopped working due to the cancer or its treatment complications.

They lost their financial independency and their ability to maintain their role as provider for the family, the role where they also could present their masculinity as the man of the house.

### **6.3 Section two: gender identity and the prostate cancer experience**

The results in the previous discussion establish a base of how the prostate cancer experience has had an influence on the participants' masculinity in its hegemonic, Arabic, and Islamic aspects. In this section, I integrate these findings with Connell's works on the gender relations model to explain how the experience with this disease would affect the participants' gender identity as Jordanian Muslim men.

Connell (2000, 2002, 2005) discusses society as multidimensional social relations between people where gender (masculinity in this case) is constructed and performed within four main dimensions: power, production, emotional, and symbolic. The four dimensions are also a place where a masculine gender identity is dynamically constructed, and what affects these dimensions in the prostate cancer experience can therefore affect this identity (Maliski et al., 2008). It will now be maintained that the influence of the participants' prostate cancer experiences on these four dimensions significantly impacts their identity as Jordanian Muslim men.

Commencing with the power dimension, Connell (2002, 2005) maintains that any given societal structure, which is patriarchal in this case (i.e., Jordanian men), creates this dimension and gives a group of people (often men) the power and the authority in society where they can demonstrate their strength and their (hegemonic) masculinity. Subsequently, the participants in this dimension appear strong and able to maintain their authority positions in society, and Jordanian Islamic society is no exception when demonstrations of masculinity are required. Indeed, in relation to the results in the first section of this chapter, the dimension of power was the most affected by the prostate cancer experience.

Several examples have been offered that illustrate that the experience with this illness was filled with various challenges that tested the participants' strength and their authority positions in society. For example, the symptoms and the difficulties the participants experienced through their cancer experience challenged their tolerance, toughness, and patience, such as the pain from the biopsy in Participant 5's case. The diagnosis of cancer, the fear of death, and the uncertainty associated with the cancer trajectory also showed how the participants as Jordanian Muslim men appeared strong or weak against their illness. Furthermore, Participants 8, 13 and 14 were an example of Arabic notions of strength by drawing on their strong Islamic faith, and

their understanding of Arabic bravery in facing cancer or death. However, regardless of sharing the same socio-cultural aspects as other participants, Participants 6, 7 and 9 are an example of those who still regarded themselves as weak in their experiences with cancer, even when trying to be strong in front of others.

The prostate cancer experience continued challenging the participants' strength through the radiotherapy procedure. Most of them were tested in their ability to tolerate and to hold a full bladder for a specific time without wetting themselves. A few of them, like Participants 6 and 8, lost their ability to hold their bladders and wet themselves, making them feel weak. Lastly, the urination and bowel problems, specifically the incontinence issue, was possibly a threat to Participant 7's and 15's (hegemonic) masculinity by their feeling of powerlessness and the embarrassment in front of people.

The results also point out the effects of being diagnosed with cancer and its treatment complications on the participants' authority positions in their Jordanian Islamic society. These positions could be disrupted by people's sympathy or any perceptions of weakness towards those men due to their illness. For example, the position of being the head of the family in Participant 12's case was threatened because he was, in the eyes of his family, a sick father who was affected by cancer. This man was clearly trying, even with his health condition, to prove his ability to control his family and maintain this patriarchal position. Likewise, the authority position as a manager (as was illustrated by Participant 4) was affected by sympathy from work colleagues.

Similar to the power dimension, the production dimension in Connell's gender relations model was also affected by the prostate cancer experience. Connell (2000, 2002) argues that men in this dimension are designated to certain tasks and responsibilities according to the history and culture of their society. In this case, as Jordanians and Muslims, the participants are responsible and accountable to protect their families and to be the source of income for the household based on their religion (Islam) and on their tradition of Arabic culture. Performing and maintaining their roles as protector and provider are therefore very important when demonstrating their Arabic and Islamic masculinities (Aslam, 2012; Inhorn, 2012; Nasser El-Dine, 2018; Siraj, 2014). The influence of the prostate cancer experience on these participants' roles as income provider and the man of the house illustrates its potential impact on their masculine identity within this dimension. As mentioned previously in this chapter, the prostate cancer experience led to difficulties with the participants' roles as protectors and providers of their families. Their

experiences with the cancer challenged their ability to maintain these roles after their diagnosis. Subsequently, most of the participants tried to limit the psychological and the financial impacts of their illness on their families. A few of them hid their diagnosis from their families because of their concerns about the distress that would ensue from the news, as in Participants 5's and 6's examples. Others, like Participants 1 and 14, tried to remain strong and show independence in front of their families during the whole cancer experience to reassure them that they were well enough, while some, like Participant 7, hid their weakness in front of their families for the same purpose. Finally, the experience with prostate cancer extended its challenges to some of the participants in their role as an income earner of the house. Those men lost this role because they stopped working either because of the diagnosis of cancer (Participant 7), or because of the treatment complications (Participant 15). Hence, losing this role had an impact on the production dimension, the second dimension where those men could demonstrate their masculinity.

The emotional dimension was the third impacted by the prostate cancer experience. Connell (2002) maintains that masculinity in this dimension is constructed and performed through the social practices of emotional attachments, desire, and commitments between people. In this case, the discussion is specifically about the Islamic heterosexual masculinity since the participants talked only about their sexual attachments and desires to females (their wives). In such a society, this would be perceived as a norm, and a norm to be publicly maintained, even if there may be alternative possibilities on this common cultural theme.

As mentioned in the third subsection of the first section, the participants' experiences with the sexual dysfunctions, such as impotency and loss of sexual desire had an influence on their sexual relationships, affecting their emotional attachment to their wives. The influence was significant on some of them (as in the stories of Participants 2, 4, and 6). These men indicated that sexual activity was important to them, and they had been deprived, as a result of a treatment side effect. It may therefore be speculated that their experiences with sexual dysfunctions possibly limited their emotional (sexual) attachments to their wives. As a result, the limitation of their emotional attachments could, and seemingly did, have a negative effect on those men's heterosexual masculine identity in this dimension. Nevertheless, most of the participants showed that they were not severely affected by their experiences with their sexual dysfunction since they coped and adapted to it. The majority like Participants 11, and 13 accepted this dysfunction as a result of aging, while some tried strategies to maintain their intimate relationships without having intercourse, as noted by Participants 1, 10 and 15. As highlighted

in Chapter 5, those three men used hugging or other physical intimacy to maintain their emotional attachments to their wives. In that case, those men could contain the influence of the sexual dysfunction in the emotional dimension as the same as in the sense of their heterosexual masculinity.

Lastly, the symbolic dimension was the fourth dimension of Connell's gender relations model where the emergence of prostate cancer may be described to have impacted. In this dimension, Connell (2000, 2002) discusses the influence of language, religion, and culture of a society in symbolising and defining what is masculine or feminine in its people. From hegemonic and an Arabic Middle Eastern cultural perspective, the real man '*Rajul*' is signified and honoured by his stoicism, strong body, sexual performance (potency), braveness and courageousness in facing death with a smile (Adibi, 2006; Al Momani et al., 2017; Aslam, 2012; Daibes, 2011; Inhorn, 2012). From an Islamic perspective, masculinity can be characterised through submitting to God's tests and to life hardships with patience and steadfastness (Arafat & Hasan, 2018; Aslam, 2012).

Reflecting on the results in the first section of this chapter, it is apparent that the participants' prostate cancer experiences have challenged most of the above hegemonic, Arabic, and Islamic masculine symbols. For example, some participants' degree of stoicism, as in Participant 5's, 6's, and 7's cases, was challenged by their experience of pain associated with the prostatic biopsy and their ability to hide feelings of anxiety, distress and perceived weakness from others through their prostate cancer experience. Furthermore, being diagnosed with cancer also tested the participants' Arabic notion of bravery and their faith in Islamic steadfastness and patience against this disease. For example, Participants 10 and 11 claimed that they were not afraid of facing death and fighting their illness, while Participants 4 and 6 were scared and thought that their lives would be over, especially in their diagnosis period. Finally, the experience with the sexual dysfunction for some men like Participants 2, and 4 was a serious threat to their potency, the symbol where they could find their sense of masculinity.

In all, the discussion above indicates that the prostate cancer experience had an impact on all four dimensions of the gender relations model, where the participants as Jordanian Muslim men could perform and represent their masculinities. The significance of this influence varied between the participants. In some cases, the prostate cancer experience had a clear impact on the four dimensions of masculinity, which could affect their gender identity as Jordanian Muslim men. On the other hand, those men and other participants tried to contain, as mentioned

in the results, this impact on the four dimensions of masculinity to maintain their gender identity. This suggests that the participants' experiences with prostate cancer not only became a challenge to their masculine identities, but also to their presentation as Jordanian Muslim men.

## **6.4 Conclusion**

This chapter has added to the previous findings chapters in the development of material that highlights the disruptive impacts and challenges that tended to interfere with the participants' own perceptions of masculinity, such as the aspects of their hegemonic, Arabic, and Islamic masculinities. As a result, the sense of 'being a man' was altered in some participants in a negative way, which reflected the more (biographical) disruption and a negative transition of their identity (liminality) in their illness experiences. However, these participants and others tried to present or maintain their masculinity in various ways to limit these disruptive impacts, such as facing cancer without fear and not giving up. This point would indicate the positive influence or motivation from masculinity on these men's responses that push them towards adaptation during their illness experience.

This chapter has also highlighted other influences of the participants' masculinity on their behaviours during their illness experiences, such as their reluctance seeking or asking for support and medical help. In most of the participants' stories, it is apparent that they wanted to appear strong and not affected by their illness in front of others. They possibly wanted to exclude others, especially their families from the influence of their cancer experiences as discussed in Chapter 5, or they preferred to act as normal and suffer in silence to meet their cultural and Islamic expectations as Jordanian Muslim men. This suggests that the influence of masculinity may prevent men from seeking or asking for support during their illness, which could negatively impact on their illness experiences.

The next chapter is the final chapter of this thesis, which will present a discussion of the main key findings from this study, its recommendations, and its strengths, and limitations.

# **CHAPTER 7: DISCUSSION AND CONCLUSION**

## **7.1 Introduction**

This chapter covers the main findings of the study and their relevance for both contemporary health care practices and future research possibilities regarding the chosen topic. It consists of five main sections. The first section presents a brief summary that includes a review of the theoretical framework and the key findings in Chapters 4, 5, and 6. This is followed by further discussion regarding important aspects of the key findings, such as masculinity and the prostate cancer experience, and a short explanation of what these key findings imply for both Jordanian Muslim men and others. Material that covers the strengths and limitations of the thesis is then presented. The fourth section of this chapter is about the implications and recommendations that may be derived from this study. The section mainly discusses the implications and recommendations for nursing practice, education, and narrative research. Finally, the chapter finishes with the main conclusions that can be elicited from the project. Here, I conclude what this thesis has added to the existing knowledge about the experience of prostate cancer, and I offer some suggestions for future research.

## **7.2 Summary of the study's theoretical framework, and the key findings**

This study raised three main research questions to explore and understand the prostate cancer experiences among a group of Jordanian Muslim men. To provide an adequate theoretical framework when answering these questions, I adopted the theoretical concepts biographical disruption and adaptation (as in coping and strategy) from Bury (1982, 1991, 2001). In using these key concepts, I also adopted the major concept of liminality (as discussed by Little et al. (1998)) to reflect the experience of disorientation and uncertainty caused by the cancer experience, and to define the transition or status of the ill person's identity due to the illness experience. I pursued the notion of liminality because I became increasingly aware during data analysis that it is indeed a major category of the experience of the cancer illness that strongly suggests that people with cancer may reach a kind of resolution where they might attain varying degrees of stability in their illness. Lastly, I implemented the important works of Connell (2000, 2002, 2005) on gender and the structure of gender relations to define some possible configurations of Jordanian hegemonic, Arabic and Islamic masculinities in the (power, production, emotional, and symbolic) relational dimensions. At the same time, I integrated the

interactions of these forms of masculinity with the prostate cancer experience to explore the impact of this illness experience on these men's gender identity.

Chapter 4 presented an overview of the participants' prostate cancer experiences through their cancer stories. It highlighted that their experience with this disease is filled with disruptive impacts and challenges that affected each participant's physical, psychological, social, and religious aspects of his life. The chapter also indicated that these challenges and the men's responses to them, varied between the participants. That is, some of these men's lives were significantly affected by the disruptive impacts and challenges, especially the impact of their cancer treatments. Other participants responded in a more positive fashion to the impacts and challenges of their illness experiences in that they managed and adapted to the disruption of the illness experience and reached a kind of stability or resolution within their illness situation. Lastly, the chapter briefly outlined that Islamic belief, the perception of illness, and the involvement of healthcare providers and family have positive and negative influences on the participants' responses and on the prostate cancer experience (i.e., biographical disruption, liminality, adaptation, and sometimes resolution).

Chapter 5 provided a deeper account of the participants' prostate cancer experiences and focused on the meaning of identity by discussing deeper analytical and descriptive details about the participants' illness experiences. Each part of their experiences showed the disruptive impacts and challenges faced by the participants and how they, in turn, responded in terms of adaptation to these impacts and challenges. In some participants' cases, it also presented a viewpoint that these disruptive impacts and challenges were strongly negative on their bodies and their lives, which, as a result, caused an obvious disruption on their biographies and/or a transition of identity, through liminality. Finally, it was maintained that each participants' families became part of the cancer experience in varying degrees of involvement, and that their involvement had both positive and negative impacts on these men's illness experiences.

Chapter 6 explored the impact of the cancer experience on the participants' gender identity. It was demonstrated that the prostate cancer experience significantly affected these men's perceived viewpoints on masculinity within its four relations dimensions: power, production, emotional, and symbolic. It maintains that the disruptive impact of the cancer experience often became a threat or a challenge to some forms of those men's Jordanian Arabic and Islamic masculinities, and in particular their hegemonic relationships. At this point, the chapter highlighted that these disruptive elements had an impact the participants' masculinity although

the men's responses to these impacts and threats varied considerably. Some found their changed masculinity to be a major concern, but others tried to contain these impacts and threats in ways that more positively reflected their sense of being a conventional 'Jordanian Muslim man'. The chapter concluded by maintaining that the participants' perspectives on their own masculinity could have both positive or negative influences on their cancer experiences by its various effects on their responses and behaviours towards their illness.

## **7.3 Discussion**

The following discussion commences with an outline of the disruptive impacts and challenges of the prostate cancer experience between the participants in this research and other men who have had similar cancer experiences. I then review the main responses to prostate cancer that presented in the participants' accounts in relation to disruption, liminality, adaptation, and resolution. Through the discussion, I highlight the influences of the participants' perceptions of illness, Islamic faith, and other contributing factors that affect their responses towards their illness experience. I then continue the discussion regarding the involvement of the participants' families and healthcare providers in their cancer experiences. Following this is a discussion about masculinity and the prostate cancer experience, which shows how this illness experience has influences that are specific to some aspects of the Arabic and Islamic masculinities. Finally, the discussion covers the complexity of this illness experience and its effects on the participants' identities.

### **7.3.1 Diversity of prostate cancer experience's impacts and challenges**

This research shows that the disruptive effects of prostate cancer create different kinds of unsettling impacts and challenges which may begin even before diagnosis. For instance, most of the participants experienced the physical and psychological discomfort that arose from pre-diagnosis urological problems, such as frequency and difficulty in urinating. Diagnostic tests also were disruptive, and many of the participants experienced pain during and after the prostatic biopsy procedure. These impacts are similar to those that have been reported among non-Muslim, non-Jordanian men in other studies, i.e., Appleton et al. (2015), Devlin et al. (2019) and Heyes et al. (2011). These studies also showed that men with prostate cancer usually suffer for a period of time from their pre-diagnosis symptoms and eventually from the diagnostic tests of prostate cancer. This indicates that there are some common impacts and challenges of the prostate cancer experience among the participants in this research project and other men with prostate cancer in the pre-diagnosis period.

Similarly, the impact of the diagnosis itself had a largely psychological impact rather than an entirely physical one, and this was highlighted in about a third of the participants' narratives. Their feelings of depression, anxiety, fear and uncertainty about their lives were also not unlike the feelings experienced by non-Muslim, non-Jordanian men in other studies e.g. Ettridge et al. (2018), and Paterson et al. (2015). The negative feelings and reactions of this group of participants was mainly based on their perceptions of cancer as a frightening fatal disease. This point raises the influence of this perception of the illness, which pushes these participants to experience the disruption and liminality (uncertainty), which was clear in the second group of the participants (as discussed in Chapter 4).

On the other hand, this research has highlighted some responses which were novel, and possibly specific to this group. For instance, 9 of the 15 participants related that they had no or little fear of cancer, which was possibly a way to represent the positive fashion in their responses to their diagnosis of cancer. Interestingly, most of the participants highlighted their Islamic faith in destiny, the will of God (Allah), and the patience that was awarded from Allah in facing life's hardships like their diagnosis with cancer. That is, they used their Islamic faith as a strategy to manage and reduce the psychological impact that comes from the diagnosis with cancer. There is considerable support in other research literature for this claim. For instance, Al-Lahim (1995) argues that the faith of destiny and the will of God are part of the articles of Islamic faith that provide a Muslim with the sense of security and contentment. This could explain why all the participants in the study eventually accepted and coped with their diagnosis of cancer. These findings demonstrate the positive impact of spirituality and the religion on managing the disruptive effects of the cancer experience, which supports the findings of other studies that discussed Islamic and non-Islamic spiritualities such as the studies of Atef-vahid et al. (2011), Lepherd (2013), Walton and Sullivan (2004), and Weathers (2018). These studies highlighted that religious men with prostate cancer, usually use their faith as a form of inner strength to accept and cope with their illness. Therefore, the influence of a positive perception of the illness and the religion (spirituality) can play a key role or be a facilitator for individuals to accept and deal with the disruption of prostate cancer, and it can be a strong factor that pushes the men's experience towards adaptation rather than ongoing disruption.

But, while religion was a source of support, its rituals also had an impact on the experience of disease. Radiotherapy is disruptive in many physical ways, but could also have a major religious impact since, for Muslims, the consequences of the radiation therapy (fear of

incontinence, need to drink water) can present major psychological stress. Treatment was scheduled for a practising Muslim participant during Ramadan required him to break his fast. The findings also revealed that most of the participants experienced urinary problems as side effects of their radiotherapy. These complications caused significant religious dilemmas that affected Islamic ritual practices. Most of the participants indicated that they were practising the five obligatory prayers. With urine dribbling (leakage) or incontinence, their ability to maintain the ritual purity to perform these prayers was challenged. As a strategy, most of them had to change their underwear or to have a shower before each prayer. They possibly had to limit their attendance at these prayers in a mosque because of these urine problems. Thus, these religious impacts and challenges are a source of disruption that affects these participants as practising Muslims. Besides the physical and psychosocial disruptive impacts of treatment complications, the religious impacts can be a double burden for these religious men because it magnifies their risks for poorer outcomes and lower quality of life than perhaps for other men (non-practising Muslims, or non-Muslims). This again suggests that the radiotherapy and its complications present specific religious challenges and disruptive effects to this group of Muslim men, which healthcare professionals need to be aware of.

This study has revealed that the experience of sexual dysfunction was another major source of disruption for some of the participants. This disruption was highly significant for at least 4 of the 15 participants narratives, i.e., they related that they felt frustrated, weak, and less masculine, all symptoms that were also evident among other men with prostate cancer in many studies, i.e., Devlin et al. (2019), Maharaj and Kazanjian (2021), Paterson et al. (2015), Rivas et al. (2016), and Walker and Santos-Iglesias (2020). Then again, the findings of this study maintain that 10 of the 15 participants at least have managed the disruptive effects of their sexual dysfunction and coped with it. Some of these ten participants adopted certain strategies with their wives to maintain their sexual life, but most of them considered themselves old, indicating that sexual dysfunction was part of their natural aging process. This phenomenon has also been seen among other men in other studies such as Appleton et al. (2015), Rivas et al. (2016), and Van Ee et al. (2018). Their studies show that many men accept their sexual dysfunction as part of their aging process or adopt different strategies, such as using sexual aids to maintain their sexual life.

Furthermore, some personal, cultural, and Islamic views on sexual matters were highlighted in this research, which related to the participants' responses and their experiences with sexual dysfunction. For instance, some of the participants reported that they would feel shy to ask

about, or practice sex at their age, which could influence them to be less concerned about their sexual dysfunction, cope with it, and move towards adaptation. Other participants indicated that the sexual need is one of their wives' rights and they as husbands need to fulfil these rights and meet their sexual needs. Subsequently, this belief created a challenge to these participants and possibly had a disruptive impact on them, or their perceptions as good husbands at least, which in turn could be a factor that pushed them towards a disruption experience. As a result, a few participants indicated that they had discussed their sexual dysfunction with their doctor and the possibility of using medical sexual aids, which of course, gives them some support and reflects an attempt towards adaptation. Other participants, as similarly found in the studies of Ahmad and Alasad (2007), Al Momani et al. (2017), and Taghipour (2009), were shy or afraid to discuss and address their sexual dysfunction in front of others, especially female health professionals. Their shyness and inability to get medical advice would be a factor in their continuing experiences of disruption and liminality that arose from their sexual dysfunction. The variety of the views on sexual dysfunction and the topic of sexual activity itself, in general, suggests the individualism of this issue among the participants and the distinct possibility of the influence of their culture, religion, and gender awareness on how they would deal with this unwanted outcome from prostate cancer treatment.

This research also examines the view of other common side effects of radiotherapy and hormonal therapy on the participants' bodies and their lives. The side effects, such as hot flushes, general weakness, bone pain, and bowel problems have created psychosocial, and consequential financial disruptive effects but the current medical practices may not pay much attention to these disruptive effects. The findings show that these side effects caused physical discomfort and limited some of the participants' abilities to perform their daily and social activities, while in a few instances, it affected their self-image as independent and respected men. The impacts of these side effects have not diminished at this point and have altered the ability to work and forced some participants to quit their jobs, which again causes more disruption to them and to their quality of life. These findings are similar to other studies such as those of Bennett et al. (2018), King et al. (2015), and Paterson et al. (2015). They highlight the importance of current medical practices taking into account the potential psychosocial and financial consequences of side effects when they discuss and plan cancer treatment with men.

This thesis shows other common disruptive impacts and challenges from the cancer experience that the participants may share with men in other studies after completing treatment (Alexis & Worsley, 2018; Bennett et al., 2018; Chambers et al., 2017). This is because the findings

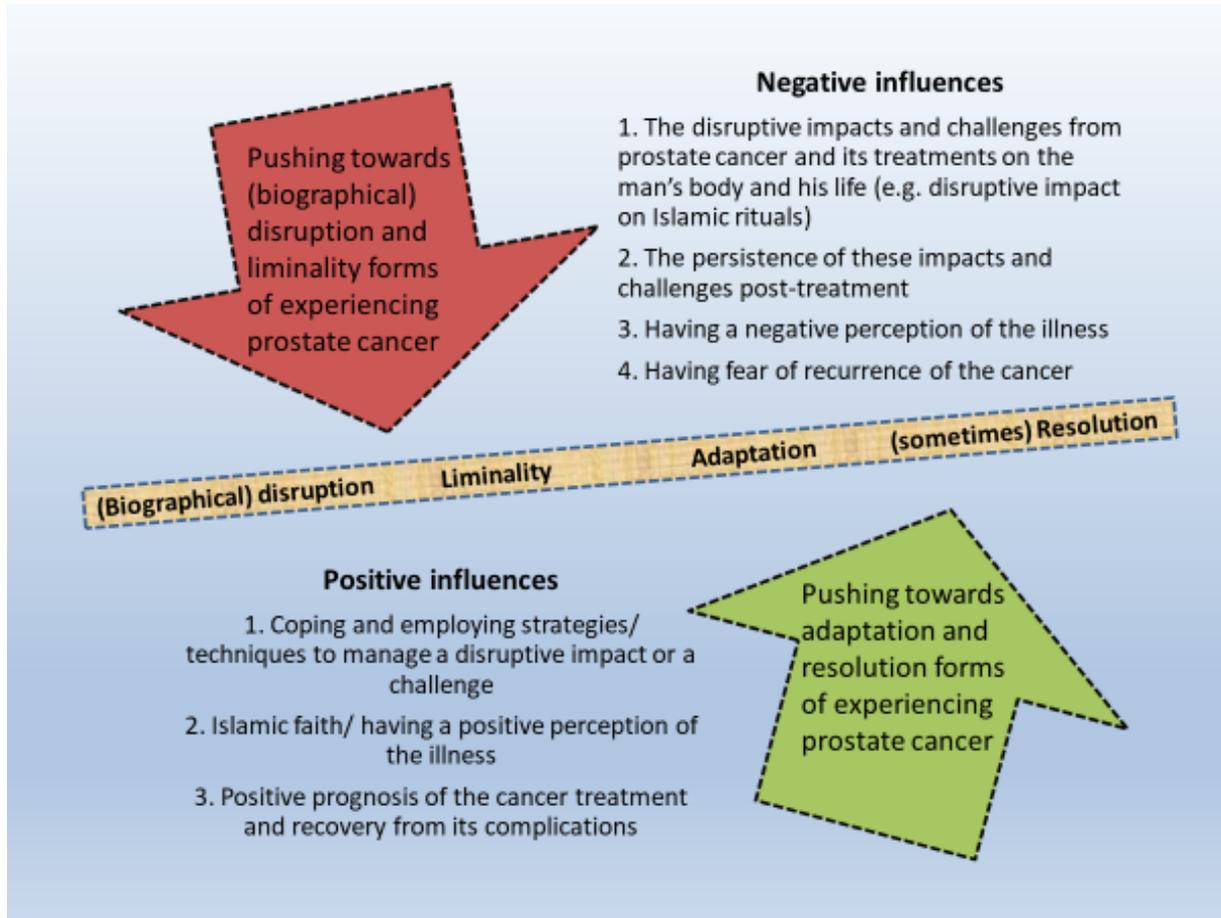
revealed that there was a significant group of participants who were still experiencing persistent adverse effects from their cancer treatments, such as urinary problems, sexual dysfunction, pain, and fatigue, after treatment had concluded. These persistent side effects consequently made this group of participants continue to have disruptive physical, psychosocial, religious, and possibly financial impacts. The findings show that these participants also felt anxiety, fear and uncertainty about their illness situation and their future life as they worried about cancer recurrence. The persistence of the disruptive impacts of the cancer experience and the fear of cancer recurrence are also evident in other studies, such as the research of Bamidele et al. (2018), Eisenberg et al. (2015), Gegechkori et al. (2017), Lisy et al. (2019), McConkey (2016), and Rivas et al. (2016). At this point, the persistence of disruptive impacts on this group of the participants' bodies, their lives and the fear of cancer recurrence had a significant negative influence, which made them experience of disruption and liminality from their illness. Thus, this study emphasises that healthcare professionals should consider the possible permanence of the disruptive impacts and challenges on men with prostate cancer. The study also stresses that continuity of support from healthcare professionals to these men (even if their bodies are free of cancer), is extremely important.

In all, this thesis adds to other research findings in that there are common impacts and challenges between the participants and other men who have similar cancer experiences. But at the same time, the thesis findings outline specific disruptive effects and challenges of this illness experience within a group of Jordanian Muslim men. This can be because of the interactions of this experience with these men's personal views of the illness experience, their Arabic culture, and Islamic faith. In addition, the findings have shown that the impact of these challenges is not limited to physical and psychological domains as healthcare professionals may think, but it can reach the social, financial, and religious aspects of men's lives. Here, this thesis addresses the importance of the healthcare professionals' awareness of the culture, and spirituality of the men affected by this cancer as well as considering all potential challenges throughout the cancer experience when they discuss and make care plans with these men.

### **7.3.2 Responses to prostate cancer among the participants**

Another key finding of this research is that the prostate cancer experience provokes different forms of responsiveness for different participants when facing cancer, i.e., (biographical) disruption, liminality, adaptation, and for some, resolution. The findings provided numerous details about the fluctuations and changes of the four forms listed above of experiencing prostate cancer among the participants across the cancer trajectory and over time. The findings

also highlighted a range of contributing factors that could have influences on the men's responses to their prostate cancer (see Figure 10).



**Figure 10:** *Forms of experiencing prostate cancer among the participants and contributing factors across the cancer trajectory*

In the pre-diagnosis period, for instance, most of the participants experienced and responded to their pre-diagnosis symptoms that had variable physical and psychosocial impacts on them in different or often similar ways. As a result, these impacts became a factor that sometimes pushed these men towards disruption and liminality experiences. This is likely because some participants suffered from pre-diagnosis symptoms for a long period without a proper diagnosis, and so the impacts from these symptoms and uncertainty about what was happening to their bodies increased the chance of experiencing more disruption and liminality. Moreover, the negative experience from the prostatic biopsy procedures for some of the participants added more disruptive impacts to their pre-diagnosis period which in turn steered them towards disruption/ liminality experiences. This indicates that the disruption and liminality forms of experiencing prostate cancer may present in some men before the diagnosis of cancer.

In the diagnosis period, the findings of this study show that the diagnosis of cancer had a strong psychological impact on several participants by causing negative feelings, such as fear, anxiety, and uncertainty due to the stigma associated with cancer. This psychological impact itself became a vital factor, which pushed these participants towards the negative side of the prostate cancer experience, where these men were more likely to experience further disruption and liminality experiences. However, over time, these participants as well as others came to accept their diagnosis of cancer and eventually learned to cope with it. This coping and acceptance of the illness was perhaps the beginning of a shift to a more positive responses, experiencing a new type (i.e., adaptation). However, the findings also highlighted the influences of the participants' perceptions of their Islamic faith on their responses in this period of their cancer experiences. This suggests that the positive perception of prostate cancer and Islamic faith may be contributing factors that push towards experiencing adaptation, while the negative perception of cancer and the consequential disruptive impacts from its diagnosis are possibly the main factors that make these men experience disruption and liminality in this period.

The types of experiences of prostate cancer among the participants continued to fluctuate after the diagnosis period. For instance, radiotherapy and hormonal therapy had disruptive impacts on participants' bodies and consequently on different aspects of their lives. Although all the participants were affected in different ways, especially from their radiotherapy, the difficulties and impacts during their treatment journey were a major factor for most of these men, which led them to experience disruption and sometimes far from feelings of adaptation and resolution. In some instances, it became increasingly obvious that the complications of their cancer treatments and its disruptive impact on their bodies, on their lives, and even their masculinity, made their experiences more disruptive and liminal in nature. However, most of the participants tried to cope with their treatment complications and employed different strategies to manage its disruptive impacts and challenges to various aspects of their lives. Some of the participants' successful management of the disruptive impacts of their cancer treatments had influences on their illness experience resulting in more positive adaptation and even resolution of a kind. This indicates that the disruptive and liminal forms of experiencing prostate cancer can be common in most men diagnosed with prostatic cancer, and quite likely observable during the treatment period. These commonly observable forms of experiencing prostate cancer were also evident in male participants within other research findings, such as the studies of Blows et al. (2012), Cayless et al. (2010), Hubbard and Forbat (2012), and Neris et al. (2020). However, it is equally likely that different forms of adaptation can be also present in this period, which perhaps

depends on how each individual male manages the disruptive impacts and challenges in this period and the significance of these impacts and challenges on his body and the aspects of his life.

As time went on in participants' cancer experience, the severity of the treatment complications and its disruptive impacts reduced in some cases. Some participants revealed that they recovered from these complications or had been in remission since their treatment. All of this, as a result, had the effect of steering these participants' illness experiences towards adaptation, and maybe even resolution in some instances. The adaptation and resolution forms of experience were seen from some participants, when they reached stability in their illnesses and felt as if their everyday life was returning to normal. On the other hand, other participants continued to struggle with the disruptive impacts and challenges from their cancer and its treatments. This struggle was likely from the persistent disruptive impacts and challenges on their bodies, their masculinity, and lives or from the fear of cancer recurrence. Hence, the persistence of ongoing and disruptive impacts from treatment complications and the fear of cancer recurrence were most likely the main factors that kept some of the participants experiencing disruption and liminality, even after completion of the treatment. This suggests that the experience of disruption and liminality from the cancer treatments can become other forms of the illness experience (i.e., adaptations, and resolution). This transformation possibly depends on the recovery from the treatments' complications or the successful incorporation of the current illness situation within everyday life. However, it is also suggested that negative forms of the prostate cancer experience may still be present long after treatment completion, as long as there remains a fear of cancer recurrence or the disruptive impacts from the cancer treatments are still significantly affecting the man's body and his life.

The changing or fluctuations between the forms of the cancer experience may not stop at the current illness situation the participants revealed at the time of their interviews. This was clearly observable in one of the participant's cases, in particular because he was once in a state of a positive adaptation experience, but the two months before the time of his interview, started experiencing colon ulcers and rectal bleeding as complications of radiotherapy. The disruptive impacts from these complications on him and his life therefore shifted his adaptation experience towards disruption and liminality. As a result, the disruption and liminality experiences were obvious at the time of his interview, reflecting his current illness situation, but this was altered from a previous, more positive adaptive state. This suggests that it is possible for the men, regardless of their current position of adaptation at time of interview, to

shift back and forth along the resolution and (biographical) disruption continuum, depending on the future of their illness situation.

To conclude, this research has shown four different forms of experiencing prostate cancer among a group of Jordanian Muslim men that presented across the cancer trajectory, changed over time, and influenced by a range of factors. The main factor is the effects of the disruptive impacts and challenges from prostate cancer and its treatments on the man's body and his everyday life, although there are other contributing factors, such as the perception of illness and Islamic faith that have effects on these experiencing forms (see Figure 10).

### **7.3.3 Health professionals and family are part of the prostate cancer experience**

The findings show that healthcare providers and the participants' families are involved at many stages in the man's cancer experience. Overall, these findings highlight that there is a positive influence throughout this involvement. For instance, for some participants, the support from the healthcare providers and family during the diagnosis and the treatment periods helped the men to accept, cope with their cancer, and even to develop strategies to ease or manage the disruptive impacts of their cancer experiences. At this point, the involvement of healthcare providers and family was a contributing factor on these participants to respond positively to the illness challenges and move towards an adaptation. This also indicates that limited involvement from healthcare providers and family resulted in less support is provided to help the men to move towards adaptation. This finding mirrors the positive effect of family and healthcare providers that has been confirmed in the studies by Ettridge et al. (2018), King et al. (2015), and Van Ee et al. (2018), all of which stressed the importance of family as support besides the healthcare professionals and including them while making a health care plan.

However, this research also highlighted that the involvement of family and healthcare providers created an additional challenge for some, if not most of the participants. In the case of the healthcare providers' involvement, the findings show that for some participants involvement becomes an unintentional barrier and limits the chance of receiving healthcare support that eases the disruption experience. An obvious example of this was the discussion about the participants' experiences of sexual dysfunction. A few of them clearly stated that they were struggling with their sexual dysfunction and uncertain about their sexual situation, which was not helped by the presence of female healthcare providers alongside their oncology doctor. This often-overlooked barrier frequently caused embarrassment and an unwillingness to discuss, and therefore receive, medical advice for their sexual issue. As a result, the involvement of

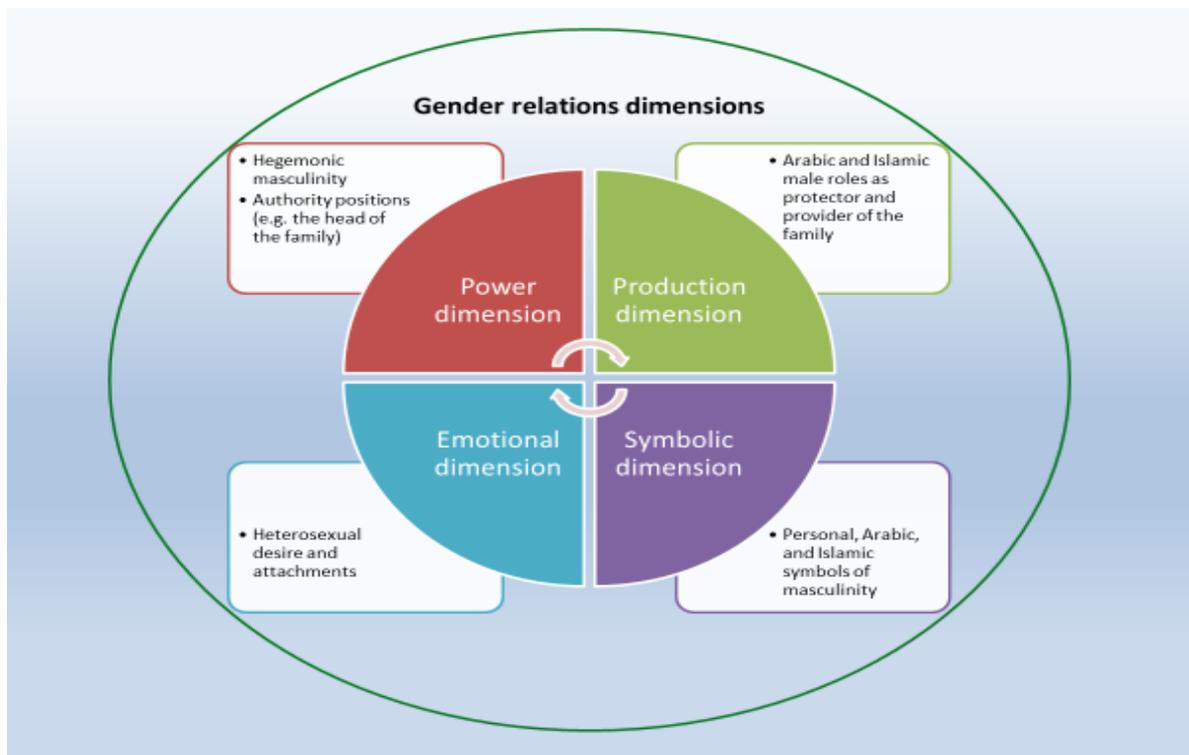
female healthcare providers unintentionally impeded their ability of getting the support that eases the disruptive impact and helps in moving towards adaptation. This issue has been discussed in different studies in Islamic countries, such as Ahmad and Alasad (2007), Al Momani et al. (2017), Iyigun et al. (2011), and Taghipour (2009). These studies show that Muslim men were often shy to talk or avoided disclosing their sexual health issues (e.g. impotency) to healthcare providers, especially females. This research confirms the difficulties involved with a gender barrier between healthcare providers and Muslim men when related to their sexual health issues. It also shows the importance of health professionals, especially males, to initiate the sexual health topic with men, to help them managing the disruptive effects of the experience of sexual dysfunction.

This thesis presents the distinct observation that the prostate cancer experience reaches beyond the affected man and impacts his family. The findings highlight that the cancer experience had disruptive psychological, emotional, and some financial impacts on most of the participants' families, which in turn created more challenges and extended the disruption experience of the men. These findings are consistent with other studies such as Cecil et al. (2010), Chambers et al. (2018), and Evans et al. (2005). These studies have discussed that the prostate cancer experience can impact men's families, which according to their common cultural practices, becomes a major issue and a concern because of the cultural roles and expectations in those societies as men. As was similarly found in the above studies, most of the participants in this research had been trying since their diagnosis with cancer to reduce and contain the psychological, emotional, and financial distresses the cancer experience caused their families. It became a big challenge to these men as Jordanian Muslims as they were trying to maintain their perceived roles as protector and provider of the family (see more in the discussion below about masculinity and the prostate cancer experience). This major challenge, besides the other disruptive impacts and challenges of the cancer experience, added more pressure for some participants that pushed them further towards disruption and liminal experiences. At this point, for some men the family's involvement was perhaps a contributing factor that influenced the experience the disruption and liminality within this illness. This demonstrates that the focus in the prostate cancer experience should not be only on the individual with cancer, but on their wider social supports, as the situation includes and impacts other people, especially their families. Thus, it is suggested that healthcare providers need to expand their focus of support to include the man's family, which consequently may ease the challenges on the man and promote health support.

In conclusion, this thesis emphasises that prostate cancer experience includes both the affected man and healthcare providers and his family. This is because inclusion or involvement of healthcare providers and the family inside the illness experience can be a significant source of support to this group of Muslim men with prostate cancer. This support, of course, had an influence on the illness experience and some men's positive responses. Yet for some at least, this involvement might also actually add to the challenges and disruptive impacts of their cancer experience. Here, the challenges from this involvement may create more disruption and liminality and make it more difficult for these men to move towards the adaptation experience.

### 7.3.4 Masculinity and the prostate cancer experience

The findings show that the disruptive impacts through the cancer experience interfere with the four relational dimensions of masculinity, i.e., the main qualities where men's hegemonic, Arabic and Islamic masculinities are constructed and performed (Figure 11). The findings reveal that these disruptive impacts challenged most of the men's masculinity within the four relational dimensions, and that for some men these impacts caused significant damage to their sense of being a man. Thus, as the following material suggests, it is probable that the negative influence on their masculinity within the four dimensions would most likely be reflected the more each individual participant experienced disruption from their illness.



**Figure 11:** *The four gender relations dimensions where the participants' masculinities can be presented and affected by the prostate cancer experience*

The findings of this current study indicated that the cancer experience had a disruptive impact for the participants, and its challenges frequently tested most of these men's physical and psychological strengths, which thereby clashed with certain aspects of their hegemonic and Arabic masculinities. For some participants, these disruptive impacts and challenges made them feel or appear weak and powerless in front of others and even disturbed their perceptions of their own presumed authority positions, as in being 'the head of the family'. As a result, this group of participants experienced greater disruption caused by their illness than perhaps other participants did. This effect has been noted to affect many men from different backgrounds, such as the studies of Alexis and Worsley (2018), Chambers et al. (2018), Maliski et al. (2008), Rivas et al. (2016), and Schildmeijer et al. (2019) who all tend to suggest that prostate cancer experience and its impacts on men's bodies and lives become a threat to masculinity, especially to the hegemonic aspect.

Since family members are frequently involved in the illness experience, this research also highlighted the disruptive impacts on the participants' roles within the production dimension as a provider and protector of the family. This is because participants' concerns about the disruptive impacts to themselves and their families were largely based on how they would fulfil their cultural and Islamic roles as the male figurehead of the family, i.e., the one who has the most responsibility for taking care of and making decisions about the household. For these participants, the negative impact of the cancer experience on their ability to maintain their masculine roles as protector or provider of the family would also reflect as additional disruption in their cancer experience. The similar negative impact of these masculine roles has also been noted on men from different cultures, evident in the studies of Cecil et al. (2010), Chambers et al. (2018), and Evans et al. (2005). This indicates that these masculine roles can be common across cultures. It is therefore suggested that the negative influence of prostate cancer on masculinity within the production dimension is also common among men regardless of their cultures.

This thesis further presents the illness's disruptive impacts on some of the participants' masculinity within the emotional dimension, i.e., their relational attachments to their wives, and in particular, their sexual performance within these intimate relationships. The disruptive impacts for these participants, especially during cancer treatments, not only diminished their sexual activities that reflected their sexuality and understandings of how they could present their heterosexual masculinity, but also eliminated one of their masculine symbols, namely their potency. Yet although this negative influence of the sexual dysfunction from the prostate

cancer experience on men's masculinity has also been addressed in many studies (e.g. Alexis and Worsley (2018); Chambers et al. (2017), and Rivas et al. (2016), sexual potency and performance in Arabic culture are one of ideal characteristics of what is a *true man*, i.e., '*Rajul*', (Aslam, 2012; Inhorn, 2012). Hence, sexual potency across different cultures can be widely linked with men's perceptions of their own masculinity, but it is a strong factor within many Islamic cultures. This helps to explain many of the participants' negative perceptions of their own masculinity which were affected by sexual dysfunction compared with others who adapted more successfully.

This thesis also demonstrates the negative effect of the cancer's disruptive impacts on the men's masculinity within the symbolic dimension. The findings showed that these disruptive impacts interfered and challenged some commonly perceived masculine symbols like stoicism and physical strength that are shared with other men in studies, such as studies by Appleton et al. (2015), Chambers et al. (2018), King-Okoye et al. (2017), and Oliffe (2006). This indicates that there is a common impact of the prostate cancer experience on men's masculinities since this illness experience can cause threats or challenges to their common perceived masculine symbols. However, as Chapter 6 shows, this study found other signifiers related to Arabic and Islamic masculinities that also interfered with the cancer experience. The diagnosis of cancer, the disruptive impacts of the cancer treatments, and the persistence of difficulties after the treatment challenged most of the participants in their Islamic faith, steadfastness against hardships from their illness, and their Arabic bravery against the possibility of death. Within the negative effect of the cancer experience on the participants' masculinity, it would seem that most of the participants tried to resist and face these disruptive impacts and challenges by presenting their versions of what they considered to be 'masculinity', which were obviously both reflections of wider sociological and more specifically culturally related views. For instance, some of the participants alluded to their Islamic strong faith, steadfastness, and Arabic bravery in facing their cancer and its disruptive impacts, and some tried to carry on with their lives as normal as a way of showing their strengths in front of others, especially their families. Here, these men's understandings of their masculinity in its hegemonic, Arabic and Islamic aspects were quite likely a motivator to not give up or let the disruption of the cancer affect them or their families. This could reflect the indirect positive influence of the men's masculinity on their behaviours during their prostate cancer experiences to uphold their stoicism and drive them towards adaptation.

It remains to note that masculinity can negatively affect the men's experiences of cancer in terms of avoiding support or asking for help. The findings of this research show how some of the participants, particularly in the pre-diagnosis period did not immediately seek medical help when they started having urological problems, choosing instead to suffer with symptoms without seeking help, even from those closest to them. Indeed, the findings make it clear that some men did not accept any kind of support from their families. The findings also indicate that most of the participants, even when suffering considerably, hid their distress by maintaining a calm appearance in front of others during and after the diagnosis period, including healthcare providers, to appear as if they were not affected by their illness or in need of support. This reluctance to seek medical help has been commonly found among men from different ethnicities and backgrounds such as Western whites, black Africans, Asians and Latin and African Americans men (Chambers et al., 2018; King-Okoye et al., 2017; Rivas et al. (2016). Thus, the participants' viewpoints of masculinity in this study, as well as others in other studies, had an influence on their behaviour to not seek help or ask for support, even when in need. This could result in men facing their cancer experience alone, where more disruption and liminality experiences usually happen.

The discussion thus far has highlighted that the disruptive impacts of the prostate cancer experience on this group of Jordanian Muslim men's masculinity can often be negative, but it can also be specifically damaging on some forms of the men's masculinity especially when these forms are linked to their personal, cultural, and religious perceptions of being a man. This discussion has also shown that the participants whose masculinity was considerably affected by these impacts, besides its negative influence on their bodies and on the main domains of their lives, experienced more disruption and liminality. Thus, this study endorses healthcare providers to be aware of the negative impacts and its consequential effects of this cancer experience on these men's masculinity, which current medical health practices may not pay much attention to, in general. Here again, it demonstrates the importance of understanding the influences of masculinity on men's health behaviour as well as healthcare professionals' awareness of this influence when they offer health support to men with prostate cancer or any illness for that matter.

### **7.3.5 Identity and the complexity of the prostate cancer experience**

This thesis highlighted that the more disruption this cancer and its treatments have on a Jordanian man's body, masculinity, and various aspects of his life, the more likely the negative impact on his sense of Muslim identity in terms of self-esteem, self-image, self-worth, and the

sense of 'being a man'. The findings show that some of the physical complications of the cancer treatments, such as general weakness, sexual dysfunction, and incontinence, had significantly worse effects on some of the participants' bodies, their masculinity, and the psychological, social, and religious aspects of their lives. As a result, they experienced an obvious biographical disruption and (liminality) a radical transition of their sense of themselves, or their identities from what many of them would perceive to be a skilful, able-bodied, and independent man to the opposite as a weak, wrecked, or disabled man. This aspect of illness amongst men has also been evident in research that examines the negative experiences of prostate cancer that significantly affected men's biographies and changed their sense of themselves, especially their gender identity (Cayless et al., 2010; Hubbard & Forbat, 2012; Navon & Morag, 2004; Neris et al., 2020; Pietilä et al., 2018). This indicates that the negative experiences of prostate cancer and its disruptive impacts on men's biographies can be seen among many men regardless of their backgrounds. On the other hand, the findings of this research have presented a group of men who appeared to have maintained their identity in a more resolute way perhaps from the determination to continue practising their lives as normal. This phenomenon has also been seen on other studies, such as the study of Hubbard and Forbat (2012), which concludes that people with cancer, even with the disruption experience, can reconstruct or change their sense of themselves in a positive way that defines who they are or become. However, in ways different from the findings of other studies, this study submits that the significant disruptive trajectory of the prostate cancer experience on the religious domain of Muslim men could cause a further and major disruption to their crucially important identities as practising Muslims.

Finally, this thesis indicates that the participants' prostate cancer stories provided a narrative window through which a group of Jordanian men might reveal often hidden or poorly understood aspects of themselves. According to Bamberg (2012) and Holloway and Freshwater (2007), narration can be a device where a narrator can make a sense of him/her self as well as his/her gendered and cultural positions. Therefore, the stories of the participants in this research show the interactions of their prostate cancer experiences within their Islamic spirituality and beliefs, which are the building blocks used to construct their identities as Muslims. The same holds true in how they positioned themselves under their Jordanian Arabic culture and its aspects of masculinity to present themselves as Jordanian men. Some of the participants highlighted during their interviews a common saying among Jordanian society: "A man/masculinity reveals themselves in (hardship) situations" to indicate that the 'real man' exists in Jordanian society through bravely and stoically facing hardship situations. This was indirectly

evident in a Jordanian study by Nasser El-Dine (2018), which highlights that men, in the current hard economic situation in Jordan, work hard in order to provide the comfort and resources needed to their partners (and may include their families). The findings indicate that the majority of participants responded in ways to their cancer with fearlessness, by fighting back and not giving up. It also shows how these men faced the challenges of their cancer experiences with courage and determination, trying to protect their families from its impacts. These men's actions have encapsulated who they are and may demonstrate what the prototypical Jordanian Muslim man would do if he were faced with the same experience.

## **7.4 Strengths and limitations of the study**

The main strengths of this study lay with its topic, theoretical framework, analytical model, and lastly the findings. In regard of the research topic, as Connelly (2013) argues, a qualitative study that attempts to uncover often hidden or difficult topics can be a strength because such research has either been hardly undertaken, or has been discussed only in limited studies. In this regard, this research addresses an important common health issue, the experience of prostate cancer – which is the most common cancer affecting men around the world – from a different cultural and religious context that has only previously been discussed in limited ways. As a result, this research can be at least viewed as adding to the knowledge within the limited literature on the illness experience of Arabic Middle Eastern and Muslim men.

The second strength is in a reliable research design that has been enhanced by theoretical framework and a unique analytical model (see Figure 2, Chapter 3). The theoretical framework of this research that consists of two main parts based on theoretical concepts, such as biographical disruption, which was developed by Bury (1982, 1991, 2001), and liminality, which was developed by Little et al. (1998). Both have been useful in understanding the cancer experience that includes the impacts on the affected person's life and identity and how he responds to these impacts. Also, of considerable value has been the use of Connell's gender relations model (2000, 2002, 2005). This part of the theoretical framework has been useful to capture possible forms of masculinity that may present in Jordanian Islamic society and to define the impacts of the cancer experience on these forms. With these two aspects of the theoretical framework, this study has thoroughly explored the experiences of prostate cancer among the participants and shown the impacts of these experiences on the men's bodies, lives, masculinity, and identity in general. Such a diverse yet focussed theoretical approach to data analysis and presentation of the findings has ensured that the study's objectives and

understanding of the prostate cancer experiences among the participants have been achieved. This effective theoretical framework has been integrated with a comprehensive analytical model. This analytical model has three approaches of narrative analysis, i.e., holistic form analysis (Tuval-Mashiach, 1998), thematic analysis (Braun & Clarke, 2006; Riessman, 1993), and Bamberg's positioning model (Bamberg & Georgakopoulou, 2008). Each approach has covered a specific aspect of the participants' stories, and each has therefore helped to present these stories in a highly effective narrative fashion. That is, while the holistic form and thematic analysis approaches focussed largely on the events of the stories, Bamberg's positioning model focuses on the participants' gender and identity, thus enhancing the aim of the study. Using these three analytical approaches and effective theoretical framework within one study allows more space to look at the participants' stories from different angles and interpretation levels, which consequently provides a clearer picture of their prostate cancer experiences.

The final strength of this study lies with its findings. The findings have captured the participants' culturally specific experiences through their cancer trajectory related to the discovery, treatment, and aftercare of prostatic cancer. In this, the findings have addressed specific challenges of this experience on a group of Jordanian Muslim men, which could be shared with other men with the same cultural and Islamic values. For example, losing the ritual purity from urine leakage or incontinence can be a challenge to all practising Muslims around the world. Therefore, these findings can be applicable to many Muslim men faced with the same challenge. Lastly, the findings have shown the complexity of this cancer experience and its influences on the participants' lives, gender, and identity. These findings are significant to the healthcare field in order to promote the care and support needed to these men. But at the same time, these findings can be useful for other humanities fields such as psychology and sociology in terms of understanding gender and identity of Jordanian Muslim men facing illness.

Conversely, this thesis has limitations. One of the key limitations is my status as insider, i.e., a Muslim man from Jordan. Being a Jordanian Muslim man with nursing experience might affect my construction and interpretations of the stories of other Jordanian Muslim men and subsequently have an impact on the subjectivity of the study. Although I have previously reflected on and addressed my own reflexivity issues (described in Chapter 3) as a way of minimising any potential influence, there is still a chance of such subjectivity and possible bias in this research.

Another possible limitation of this study is related to the sample size and the characteristics of the participants. Holloway and Freshwater (2007) indicate that findings of narrative research are not generalisable since this kind of research often has a small sample. The sample size of this study is fifteen Jordanian Muslim men with prostate cancer who had radiotherapy and hormonal therapy. Hence, the findings of this study cannot be generalised on other Jordanian Muslim men undergoing a different type of cancer treatment, or are not Muslim, as is the case of Jordanian Christians. In addition, the sample of this research has not included other people who are involved in this illness experience, such as the families of the participants and healthcare providers. The findings have highlighted the involvement of these people in the men's cancer experiences, which indicates that people can be significant sources of information, expanding the understanding of the illness experience. In this case, the understanding of the illness experience in this study is limited to the participants' point of view and not their families' or healthcare providers' perspectives that would make the picture of the prostate cancer experience richer. Therefore, there is a need for further research studies that include different type of samples to get a better understanding of the experience of prostate cancer in Jordan.

These limitations were all considered and discussed with my two supervisors. They both had an important role, for example, in monitoring my analysis and interpretation of the participants' stories and searching for other possible interpretations (truths) within these stories.

## **7.5 Implications and recommendations**

This thesis has addressed a few important issues that should be of considerable interest to nurses and nursing practice, especially in Jordan, but also whenever a nurse is preparing care plans and delivering nursing support to men who share some or many similarities with the participants of this study, i.e., caring for a Muslim male under treatment for the most common cancer in males worldwide.

One main issue is that prostate cancer experience can cause disruptive impacts and challenges on the religious aspect of the life of a (practising) Muslim man. Therefore, this thesis recommends nurses either within or outside Jordan to discuss with a Muslim patient about what possible impacts and challenge he may face and how to meet his religious needs. Nurses can refer him to a religious person (*Imam*) or services inside or outside hospital not only to provide support to accept or cope with his illness but also to give him an Islamic advisory opinion or '*Fatwa*' on how to maintain rituals with his illness. The thesis also provides nurses some coping

strategies techniques employed by some participants in the case of urine incontinence or leakage, such as using a tissue or through introducing Western practices of using disposable pads, to protect their underwear or adjusting the prayer times to manage two prayers within a short period. However, the main message for nurses in this instance is that most Muslim men undergoing treatment for prostatic cancer may require professional advice and assistance about dealing with incontinence or leakage from the nurse. This should be handled with due care and consideration for the psychological, social, and religious needs of such individuals.

Another main issue is about collecting and discussing sensitive information, such as urinary problems and sexual dysfunction, with a (Jordanian) Muslim patient, especially in presence of female healthcare providers. Added to that, the influence of the man's masculinity and desire to maintain stoicism can prevent him from addressing his health complaints or seeking medical help, which also causes another barrier to collecting health information and determining his health needs. In Jordan, male and female healthcare providers work together with some exemptions, such as delivery word. Therefore, the thesis recommends healthcare providers consciously make a place and time for male only conversations regarding sensitive health topics such as sexuality. In addition, female healthcare providers need to be aware that they may need to leave the room for periods of time during outpatient appointments. The thesis further suggests that certain sensitive information may sometimes be addressed and discussed using a male nurse who is familiar with a man's cultural and religious views. The thesis generally recommends nurses, regardless of gender, take the initiative to approach a male patient even if a man does not show he is in need or explicitly ask for help; asking him about his health and illness situation, as well as offering their health support.

This thesis has also indicated the generally positive influence of family involvement on the affected Muslim man when facing his cancer experience. There is usually good support from this family involvement because of shared cultural and religious belief systems, that helps the man to accept and cope with the cancer experience whilst maintaining his perceived role within the family. Thus, the recommendation is to ensure the appropriate inclusion of family in making a comprehensive care plan to maximise the support for the affected man. However, it is accepted that for some men, the family's involvement can cause more pressure and create another challenge to his cancer experience, and therefore, it is generally recommended that nurses carefully assess family dynamics and perhaps openly ask or suggest to men that they bring family members and include them within care plan.

Looking from educational perspective, nursing education, especially in Jordan, but also perhaps worldwide, should also include information about the influence of perceptions of masculinity on men's health behaviours, and particularly on the possible impact of Islamic culture on males undergoing treatment for prostatic cancer, or even other forms of cancer. The study has highlighted that most of the participants were reluctant to seek medical help or show they were affected by their cancer in order to uphold their cultural and religious expectations as Jordanian Muslim men. This shows the influences that affect a Jordanian male's viewpoint on masculinity, and to an extent, the influence of this viewpoint (or vice versa) on Muslim belief systems. It is therefore a critical element that needs to be considered in healthcare education, especially in health promotion programmes. For instance, healthcare professionals within the Ministry of Health in Jordan and no doubt in other countries need to consider the influence of men's masculinity on approaching a prostate cancer screening programme, or even perhaps how they can encourage more men to seek out health services. This is a well-recognised issue within men's health around the world.

From an academic and research-based perspective, this thesis has significant implications for the use of the narrative approach when considering an illness trajectory. The analytical model of this study has three approaches of narrative analysis: thematic analysis, holistic form analysis, and Bamberg's positioning model. The three analytical approaches are integrated together in three analytical steps that serve three different levels of analysis, which eventually provide researchers with one data set, such as prostate cancer stories in this study, and a deeper understanding of illness experience and its impacts on people's lives and their identity. The three analytical approaches also show their effectiveness in applicability on Jordanian Arabic narrative and in covering the research's objectives. This indicates the susceptibility of implementation of the research analytical model or any of these three narrative approaches firstly on Arabic narrative text and/or secondly on any studies with research objectives similar to the aims of this study.

Furthermore, this study demonstrates that selected theoretical concepts such as 'biographical disruption' and 'liminality' can be very useful in understanding any cancer experience among men who may share similarities with the participants of this study, such as Arabic Middle Eastern and Muslim men. These concepts in the illness narrative were found to be highly valuable when attempting to conceptualise the given issue. As a result, these concepts have helped in understanding the experience of this cancer from particular cultural and religious contexts and have suggested more general implications for wider socio-cultural considerations.

This, of course, indicates that the process of illnesses such as prostate cancer, its effects on men's lives, and how they respond to it, can contain aspects of response and behaviour that are both culturally specific but also often shared among men regardless of their backgrounds.

Lastly, because this thesis also adopted Connell's works (2000, 2002, 2005) on gender relation, there is the possibility that this thesis can contribute to future theoretical development; not only in gender studies in general, but also in studying gender within specific illness narratives. Connell's work, especially the gender relations model, was of great help when exploring possible forms of hegemonic, Arabic, and Islamic masculinities that may present in Jordanian Islamic society. This gender relations model has also helped in defining the areas (i.e., relational dimensions) where masculinity can be affected by the prostate cancer experience. This thesis, therefore, provides more evidence on the validity of Connell's works not only on understanding the masculinity of Jordanian Muslim men but also understanding how the illness experience may affect men's masculinity in general.

## **7.6 Conclusion**

This study has explored different experiences of prostate cancer among a group of Jordanian Muslim men by utilising a significantly modified research approach to narrative inquiry. The study revealed both negative experiences (biographical disruption, liminality) and positive experiences (adaptation, and [possible] resolution) across the cancer trajectory and the fluctuations of these experiences over time. The study highlights different kinds of disruptive impacts and challenges that this group of Muslim men faced in different periods of their cancer trajectory (pre-diagnosis, diagnosis, treatment, and post-treatment) as well as how these men responded and adapted to them. The study indicates that these impacts and challenges and their consequential effects not only significantly affect the men's physical health, but also different and important aspects of their lives (i.e., psychological, social, and religious). Furthermore, the study addresses the complexity of this illness experience within a specific group of Muslim men, and examines its impact and interactions with their bodies, lives, masculinity, identity, culture, spirituality, and even with other people such as their families and health care personnel. As a result, the study explains that these interactions have the influence not only on the forms (negative or positive) of experience that the men are experiencing, but also on the men's responses and behaviours towards these experiences, thus providing a guide to the most appropriate responses within the health care setting.

This study, therefore, can be useful guidance for healthcare professionals, and perhaps especially nurses, around the world who deal with men who share similar socio-cultural backgrounds and behaviours. It can also be a source of knowledge about the prostate cancer experience among Jordanian Muslim men, and about the effects of this disease on their gender and identity. But at the same time, this guidance or understanding can be limited and should be used carefully since it cannot be generalised to all Jordanian or Muslim men with prostate cancer. Thus, it may be highly beneficial to consider further research on the experiences of prostate cancer among Jordanian men that includes men with different religious beliefs and practices (e.g., Jordanian Christians), types of treatment (e.g., prostatectomy), or with families of these men and healthcare providers who deal with these men, to get different perspectives of this particular type of cancer experience. Finally, the study recommends that further studies in nursing, psychosocial, and social health research areas, develop theoretical concepts that reflect other Arabic and Islamic contexts to get a better understanding of this experience among Muslim men.

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# APPENDICES

## Appendix 1: Confidentiality agreement



### Confidentiality Agreement

For transcriber, translator, research assistant, and the researcher supervisor

Project Title: Exploring prostate cancer experience among Jordanian Muslim men

Principal

Investigator: Abdulmalik Hasanain

I \_\_\_\_\_, have the role in this study of \_\_\_\_\_.

I agree to ensure that the audiotapes of the interviews and its transcriptions will remain confidential to **Abdulmalik Hasanain** and myself.

I agree to take the following precautions:

1. I will ensure that no person, other than the principal investigator, hears the recordings of the interviews or sees its transcriptions.
2. I will ensure that no other person has access to my computer/device.
3. I will delete the files from my computer/device once my role in this study has been completed.
4. I will not discuss any aspect of the recording with anyone except the principal investigator.

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

## Appendix 2: The ethical approval from Victoria University of Wellington



Phone 0-4-463 5480  
Email susan.corbett@vuw.ac.nz

### MEMORANDUM

|         |   |
|---------|---|
| TO      | Malik Hasanain  |
| COPY TO | Dr Martin Woods   |
| FROM    | AProf Susan Corbett, Convener, Human Ethics Committee   |
| DATE    | 28 July 2017  |
| PAGES   | 1   |
| SUBJECT | <b>Ethics Approval: 25052</b><br>Exploring prostate cancer experiences among Jordanian Muslim men |

Thank you for your application for ethical approval, which has now been considered by the Standing Committee of the Human Ethics Committee.

Your application has been approved from the above date and this approval continues until 1 September 2019. If your data collection is not completed by this date you should apply to the Human Ethics Committee for an extension to this approval.

Best wishes with the research.

Kind regards



Susan Corbett  
Convener, Victoria University Human Ethics Committee

## Appendix 3: The IRB number and the request for continuing approval from King Hussein Cancer Centre



### King Hussein Cancer Center Institutional Review Board

#### REQUEST FOR CONTINUING APPROVAL

|   |   |
|---|---|
| <b>Project Title:</b>                                     | Exploring Prostate Cancer experiences among Jordanian Muslim men                    |
| <b>IRB Number:</b>  | 17 KHCC 82  |
| <b>Principal Investigator from KHCC:</b>                  | Dr. Jamal Khader  |
| <b>Telephone Number:</b>                                  | (+962) 6 53 00 460  |
| <b>Fax Number :</b>                                       |   |
| <b>Principal Investigator from outside KHCC:</b>          | Mr. Abdulmalik Hasanain   |
| <b>Principle investigator signature*</b>                  |  |
| <b>*I testify that the changes are as detailed below.</b> | Abdulmalik Hasanain   |

**What is the Status of Your Research Project?**

- Active (Still enrolling subjects)  
 Closed to subject enrollment, but subjects still receiving or involved with research intervention.  
 All research interventions completed, but research open for data analysis and follow up of subjects.  
 All research related activities completed; request termination of research with IRB addenda

**Briefly Describe Study (not more than 3 lines):**

The project is a qualitative study to explore prostate cancer experiences among Jordanian Muslim men. The information from this project will be used in my PhD dissertation.

**STUDY FINDINGS:**

**Are there results to report at this time? (not more than 3 lines):**

- Yes, please provide a brief summary of the goals and results obtained in the study  
 No, explain why

Still in the analysis stage

**On-site subject enrollment Since Date of last IRB Approval and Total:**

|  |    |
|--|----|
| Total Number of subjects enrolled at KHCC                | 15 |
| Total Number of subjects enrolled since last IRB         | 15 |
| Total Number of subjects enrolled from other institution | 0  |

**Did KHCC subject(s) suffer any unanticipated or serious adverse event?**

No       Yes, How many

If yes, summarize the reported events, and briefly describe their nature and relationship to the study. Attach available safety reports, incident reports, and data or safety reports. Provide information concerning relevant problems or issues affecting the study.

**Based on your knowledge of adverse events that have occurred in subjects in this study do you feel that there has been an increase in risks to subjects?**

Not applicable (No adverse events have occurred)  
 Yes, please explain your assessment (if necessary, attach extra sheets)  
 No, please explain your assessment (if necessary, attach extra sheets)

**Were any subjects removed from your study without their consent?**

Yes  
 No

If yes, how many subjects, and give reason in each case.

**Did anybody withdraw themselves from your study?**

Yes  
 No

If yes, how many subjects, and give reason in each case.

**Were there any complaints about the study?**

Yes  
 No

If yes, give reason for each case.

**FOR IRB USE ONLY**

|  |          |
|--|----------|
| <input type="checkbox"/> Approved by expedited review        | Comments |
| <input type="checkbox"/> Approved by convened IRB            |          |
| <input type="checkbox"/> Not approved, resubmission required |          |
| Signature of IRB chair or Designee                           | Date     |

## Appendix 4: Information sheet Victoria University of Wellington



### ***Exploring prostate cancer experiences among Jordanian Muslim men***

#### **INFORMATION SHEET FOR PARTICIPANTS**

Thank you for your interest in this project. Please read this information before deciding whether or not to take part. If you decide to participate, thank you. If you decide not to take part, thank you for considering my request.

#### **Who am I?**

My name is *Abdulmalik Hasanain* and I am a *doctoral* student in *Graduate school of Nursing Midwifery and Health* at Victoria University of Wellington. This research project is work towards my *doctoral thesis*.

#### **What is the aim of the project?**

This project is to *explore how Jordanian Muslim men experience their lives with prostate cancer, and their adaptations to this experience*.

This research has been approved by the Victoria University of Wellington Human Ethics Committee [25052], and the King Hussein Cancer Centre Institutional review board [17 KHCC 82].

#### **How can you help?**

If you agree to take part, I will interview you in a private room in the King Hussein Cancer Centre or where you prefer, such as your home. I will ask you questions about *prostate cancer*. The interview will take *45-60 minutes*. I will record the interview and write it up later. You can stop the interview at any time, without giving a reason. You can withdraw from the study up to four weeks after the interview. If you withdraw, the information you provided will be destroyed or returned to you.

#### **What will happen to the information you give?**

This research is confidential. I will not name you in any reports, and I will not include any information that would identify you. Only my supervisors, my research assistant, a transcriber and I will read the notes or transcript of the interview. All who read the transcripts of the interview will sign a "confidentiality agreement form". The interview transcripts, summaries and any recordings will be kept securely and destroyed 5 years after the research ends.

### **What will the project produce?**

The information from my research will be used in my *PhD dissertation*. You will not be identified in my report. I may also use the results of my research for conference presentations, and academic reports. I will take care not to identify you in any presentation or report.

### **If you accept this invitation, what are your rights as a research participant?**

You do not have to accept this invitation if you don't want to. If you do decide to participate, you have the right to:

- choose not to answer any question;
- ask for the recorder to be turned off at any time during the interview;
- If you feel any kind of discomfort or stressed from any question during the interview, you have the right to not answer.
- withdraw from the study at any time after your interview;
- ask any questions about the study at any time;
- receive a copy of your interview recording (if it is recorded);
- read over and comment on a written summary of your interview;
- agree on another name for me to use rather than your real name;
- be able to read any reports of this research by emailing the researcher to request a copy.

### **If you have any questions or problems, who can you contact?**

If you have any questions, either now or in the future, please feel free to contact either:

#### **The researcher:**

Name: Abdulmalik Hasanain

University email address:

[Malik.Hasanain@vuw.ac.nz](mailto:Malik.Hasanain@vuw.ac.nz)

#### **The researcher supervisor:**

Name: Martin Woods

Phone: +64 (04) 463 5034

Email address: [martin.woods@vuw.ac.nz](mailto:martin.woods@vuw.ac.nz)

#### **The researcher assistant from King Hussein Cancer Centre:**

Name: Dr Jamal Khader

Phone: 06-5300460

Email address:  
[JKhader@khcc.jo](mailto:JKhader@khcc.jo)

### **Human Ethics Committee information**

If you have any concerns about the ethical conduct of the research you may contact the Victoria University HEC Convener: Associate Professor Susan Corbett. Email [susan.corbett@vuw.ac.nz](mailto:susan.corbett@vuw.ac.nz) or telephone +64-4-463 5480.

Or

King Hussein Cancer Centre IRB Coordinator: Linda Kateb. Email [irboffice@khcc.jo](mailto:irboffice@khcc.jo), [lkateb@khcc.jo](mailto:lkateb@khcc.jo) or telephone +962-6-5300460/extension 1669

## دراسة عن تجربة سرطان البروستاتا عند المسلمين في الأردن معلومات عن الدراسة

أود أن أشكر رغبتك في هذه الدراسة. أرجو أن تقرأ المعلومات في هذه الاستمارة قبل أن تقرر أو ترفض المشاركة في هذه الدراسة. سواء أقررت في المشاركة في هذه الدراسة أم لا، فشكراً لك.

### من هو الباحث؟

أنا عبد الملك حسنين، طالب دكتوراه في كلية خريجي التمريض والقبالة والصحة في جامعة فيكتوريا في ويلنغتون/ نيوزيلاندا. هذه الدراسة هي مشروع بحثي في رسالتي للدكتوراه.

### ما هدف هذه الدراسة؟

هدف هذه الدراسة هو معرفة تجربة المسلمين المصابين بسرطان البروستاتا مع هذا المرض، وكيفية التأقلم مع هذه التجربة.

تم الموافقة على هذه الدراسة من قبل لجنة الأخلاق البشرية في جامعة فيكتوريا في ويلنغتون رقم (٢٥٠٥٢) ولجنة الأخلاق البشرية في مركز الحسين للسرطان رقم (١٧ ٨٢).

### كيف يمكنك المساعدة؟

إذا وافقت على المشاركة في هذه الدراسة فسوف أجري معك مقابلة في غرفة خاصة في مركز الحسين للسرطان أو في أي مكان تفضل، في بيتك على سبيل المثال. في المقابلة سوف أسألك عدة أسئلة عن تجربتك مع سرطان البروستاتا. المقابلة سوف تكون من خمس وأربعين دقيقة إلى ساعة. سوف أسجل هذه المقابلة ثم أكتب عنها لاحقاً. يمكنك أن تُوقف المقابلة في أي وقت ومن دون أن تعطي أي سبب لذلك. كما يمكنك أن تنسحب من هذه الدراسة في أي وقت لفترة تصل إلى أربع أسابيع من مقابلتك المسجلة. في حال انسحبت من هذه الدراسة فإن المعلومات التي قدمتها سوف تتلف أو ترجع إليك.

### ماذا سوف يحدث للمعلومات التي قدمتها؟

هذه الدراسة تعامل بسرية، أي أن أسمك لن يكون في أي تقرير من هذه الدراسة ولا حتى أي معلومة قد تُعرف بك. فقط أنا ومشرقي ومساعدتي من محلل ومترجم قادرين على قراءة الملاحظات ونص المقابلة. مع العلم بأن كل منهم سوف يوقع على "نموذج حفظ سرية المعلومات". كل نصوص المقابلة والملخصات أو إي تسجيل سوف يتم حفظه بشكل آمن، ثم سيتم تلفة بعد خمس سنوات من نهاية الدراسة.

### ماذا سينتج من هذه الدراسة؟

المعلومات من هذه الدراسة سوف تستخدم في رسالتي العلمية للدكتوراه ولن يتم تعريف عنك في تقرير الدراسة. كما أنني قد أستخدم نتائج هذه الدراسة في تقارير أكاديمية أو محاضرات في مؤتمرات علمية.

## إذا قبلت المشاركة، ما هي حقوقك كمشارك في هذه الدراسة؟

ليس شرطاً أن تقبل المشاركة في هذه الدراسة إذا لم ترد، فلك الحرية الاختيار الكاملة في المشاركة في هذه الدراسة. إذا أردت المشاركة فلك الحقوق التالية:

- الحرية لعدم الإجابة لأي سؤال.
- طلب إيقاف المسجل في أي وقت خلال المقابلة.
- حرية الانسحاب من الدراسة في أي وقت لفترة تصل لأربع أسابيع بعد المقابلة.
- أن تسأل أي سؤال عن الدراسة في أي وقت.
- تحصل على نسخة من مقابلتك.
- قراءة أي تعليق كُتب في ملخص مقابلتك.
- الموافقة على اختيار اسم آخر غير اسمك الحقيقي ليستخدم في الدراسة.
- قراءة أي تقرير من هذه الدراسة وتُطلب نسخة من الباحث عن طريق بعث رسالة لبريده الإلكتروني.

## إذا عندك أي سؤال أو مشكلة، مع من تتواصل؟

إذا عندك أي سؤال سواء الآن أو لاحقاً، أرجو أن تتواصل مع أي من:

الباحث:

عبد الملك حسنين

بريد الإلكتروني للجامعة:

[Malik.Hasanain@vuw.ac.nz](mailto:Malik.Hasanain@vuw.ac.nz)

مساعد الباحث:

الاسم: الدكتور جمال خضر

رقم الهاتف:

البريد الإلكتروني:

[JKhader@khcc.jo](mailto:JKhader@khcc.jo)

## معلومات عن لجنة الأخلاق البشرية

فيكتوريا إذا عندك أي تعليق أو مشكلة متعلقة بأخلاقيات البحث، يمكنك أن تتواصل مع مسؤولة لجنة الأخلاق البشرية في جامعة

[susan.corbertt@vuw.ac.nz](mailto:susan.corbertt@vuw.ac.nz) الأستاذ مساعد/ سوزان كوربيت، رقم الهاتف: +6444635480، البريد الإلكتروني:

أو مع منسقة لجنة الأخلاق البشرية في مركز الحسين لسرطان: لندا كاتب. رقم الهاتف: 065300460/ فرعي 1669

البريد الإلكتروني: [irboffice@khcc.jo](mailto:irboffice@khcc.jo), [lkateb@khcc.jo](mailto:lkateb@khcc.jo)

# Appendix 5: Consent form Victoria University of Wellington



## Exploring prostate cancer experiences among Jordanian Muslim men

### CONSENT TO INTERVIEW

This consent form will be held for 5 years.

Researcher: *Abdulmalik Hasanain, Graduate school of Nursing Midwifery and Health, Victoria University of Wellington.*

- I have read the Information Sheet and the project has been explained to me. My questions have been answered to my satisfaction. I understand that I can ask further questions at any time.
- I agree to take part in an audio recorded interview.

I understand that:

- I may withdraw from this study up to four weeks after the interview, and any information that I have provided will be returned to me or destroyed.
- The information I have provided will be destroyed 5 years after the research is finished.
- Any information I provide will be kept confidential to the researcher and the supervisor. I understand that the results will be used for a *PhD* report and a summary of the results may be used in academic reports and/or presented at conferences.
- My name will not be used in reports, nor will any information that would identify me.
- *[OR]* I consent to information or opinions which I have given being attributed to me in any reports on this research: Yes  No
- I would like a copy of the transcript of my interview: Yes  No
- I would like a summary of my interview: Yes  No
- I would like to receive a copy of the final report and have added my email address below. Yes  No

Signature or initials of participant: \_\_\_\_\_

Date: \_\_\_\_\_

Contact details: \_\_\_\_\_

## دراسة عن تجربة سرطان البروستاتا عند المسلمين في الأردن الموافقة على إجراء مقابلة

هذه الموافقة سارية المفعول لمدة خمس سنوات

الباحث: عبد الملك حسنين، كلية خريجي التمريض والقبالة والصحة في جامعة فيكتوريا في يلينغتون/ نيوريلاندا

• لقد قرأت استمارة "معلومات عن الدراسة" وتم شرح مضمون الدراسة لي والإجابة عن أسئلتني جميعها.  
كما أنا على علم بأنني أستطيع أن أسأل أي أسئلة أخرى وفي أي وقت.

• أنا أوافق على المشاركة في إجراء مقابلة مسجلة صوتياً.

كما أنا على علم بأنني:

• أستطيع أن أنسحب من هذه الدراسة في أي وقت لفترة تصل إلى أربع أسابيع من بعد إجراء المقابلة المسجلة.  
وبناءً على ذلك فإن أي معلومة قد قدمتها سوف ترجع لي أو يتم تلفها.

• المعلومات التي قدمتها سوف يتم تلفها بعد خمس سنوات من نهاية الدراسة.

• أي معلومة قد قدمتها سوف تحفظ بسرية من قبل مشرفي الباحث والباحث ومساعديه من محلل ومترجم. كما  
أنا على علم بأن نتائج هذه الدراسة سوف تستخدم في رسالة الدكتوراه، ويمكن أن تستخدم في تقارير أكاديمية أو  
تقدم في مؤتمرات.

• سيبقى اسمي في طبي الكتمان ولن يستخدم في أي تقرير من هذه الدراسة.

- |    |     |   |
|----|-----|---|
| لا | نعم | • أوافق على أي معلومة أو رأي قد تقدمتها للمساهمة في أي تقرير من هذه الدراسة       |
| لا | نعم | • أود نسخة من نص مقابلي   |
| لا | نعم | • أود ملخص عن مقابلي  |
| لا | نعم | • أود نسخة من التقرير النهائي لهذه الدراسة تصل إلى بريدي الإلكتروني الموجود أدناه |

توقيع المشترك: -----

التاريخ: -----

بيانات التواصل: -----

## Appendix 6: Informed consent King Hussein Cancer Centre



King Hussein Cancer Center

Institutional Review Board

مركز الحسين للسرطان

اللجنة المؤسسية

إقرار بالموافقة على بحث بدون فائدة مباشرة للمشاركين

### Informed Consent for Research with No Direct Benefits to Participant

ملاحظة للباحث: يرجى الأخذ بعين الاعتبار أن بعض المصطلحات والنقاط الواردة في هذا النموذج يمكن ألا تتناسب وطبيعة لدراسة التي ستقوم بها. يرجى الاتصال باللجنة المؤسسية للمشورة بكيفية تحويل (تعديل) هذا النموذج ليتناسب أكثر وطبيعة دراستك.

**عنوان البحث :** دراسة عن تجربة سرطان البروستاتا عند المسلمين في الأردن

**الجزء الأول – معلومات للمشاركة في البحث:**

**أ. الغرض من البحث:**

هو معرفة تجربة المسلمين المصابين بسرطان البروستاتا مع هذا المرض، وكيفية التأقلم مع هذه التجربة

**ب. وصف البحث:**

إذا وافقت على المشاركة في هذه الدراسة فسوف أجري معك مقابلة في غرفة خاصة في مركز الحسين للسرطان. في المقابلة سوف أسألك عدة أسئلة عن تجربتك مع سرطان البروستاتا. المقابلة سوف تكون من خمس وأربعين دقيقة إلى ساعة. سوف أسجل هذه المقابلة ثم أكتب عنها لاحقاً. يمكنك أن تُوقف المقابلة في أي وقت ومن دون أن تعطي أي سبب لذلك. كما يمكنك أن تتسحب من هذه الدراسة في أي وقت لفترة تصل إلى أربع أسابيع من مقابلتك المسجلة. في حال انسحبت من هذه الدراسة فإن المعلومات التي قدمتها سوف تُلغى أو تُرجع إليك.

**ج. المدة المتوقعة للدراسة:**

المدة اللازمة لانتهاء دراسته كاملة : 3 سنوات

مدة مشاركة المريض في هذه الدراسة : مقابلة صوتية مسجلة لمدة 45-60 دقيقة

**د. عدد المشاركين بالدراسة 8-12**

**هـ. عدد المراكز المشاركة 1**



#### و. المخاطر والانزعاجات المحتملة:

لا يوجد مخاطر في هذه الدراسة لكن قد يكون انزعاجات نفسية محتملة (مثل عدم ارتياح، قلق، جهد) من أسئلة المقابلة أو من المقابلة نفسها، فإن وجدت هذه الانزعاجات، سوف أوقف المقابلة والتسجيل. ثم سيتم إعلام الباحث الرئيسي من مركز الحسين للسرطان الدكتور جمال خضر والأخصائي الاجتماعي المشارك في هذه الدراسة لتقديم المساعدة اللازمة.

#### ز. الفوائد المرجوة :

المعلومات من هذه الدراسة سوف تستخدم في رسالة الدكتوراه للباحث الرئيسي، كما أن نتائج هذه الدراسة قد تستخدم في تقارير أكاديمية أو كمحاضرات في مؤتمرات علمية، والتي بدورها قد تساهم في تحسين أو تطوير خدمة الطبية التي يتلقاها مريض سرطان البروستاتا في الأردن أو في العالم.

#### ح. البدائل عن المشاركة ( إن وجدت ):

لا يوجد

#### ط. تكاليف المشاركة:

لا يوجد

#### ي. المكافآت المالية:

لا يوجد

#### ك. التعويضات / المعالجات:

تعويض نفقات استخدام المواصلات من وإلى المركز من أجل إجراء المقابلة ويحد أعلى 10 دنانير، تقدر بناءً على تقدير المسافة.

#### ل. المشاركة الطوعية:

المشاركة في هذه الدراسة طوعيه وإذا قررت عدم المشاركة فانك لن تتعرض لأي مضايقات أو لفقدان حقك المشروع في المعالجة.

#### م. السرية:

كمشارك في هذه الدراسة ستكون هويتك ومحتويات ملفك الطبي سرية في جميع المنشورات المتعلقة بنتائج الدراسة كما سيبقي رقم سجلك الطبي سري في الحدود التي يسمح بها القانون. كما أن إسمك لن يسجل أو يذكر في المقابلة و سوف يستخدم مبدأ الترميز في المقابل، كمقابلة 1،2،3.....



Informed Consent for Research with No Direct Benefits to Participant

والقوانين المطبقة بهذا الخصوص سيتم تزويدك بنسخة موقعة من هذا الإقرار .

### ن. : إنهاء المشاركة:

أن قرارك بالانسحاب من الدراسة لن يؤثر على تطبيقك للخدمة العلاجية المعتمدة والمتوفرة في مركز الحسين للسرطان. سيتم إبلاغك بأي نتائج هامة جديدة تظهر خلال تطورات البحث وبناءً عليه يحق لك اتخاذ القرار بالاستمرار بالمشاركة أو التوقف عنه.

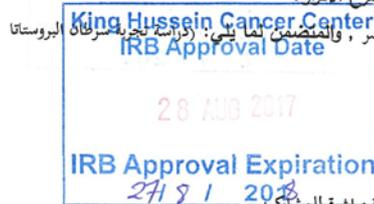
### • الأشخاص الذين يمكن الاتصال بهم:

- في حالة وجود أي استفسار عن الدراسة أو أسئلة محددة تتعلق بهذه الدراسة وفي حالة حدوث أي مضاعفات تتعلق بالدراسة نرجو الاتصال ب الدكتور جمال خضر على هاتف رقم مركز الحسين للسرطان رقم 5300460.
- في حالة وجود أي أسئلة عامة أو أسئلة تتعلق بحقوق المشارك عليك الاتصال باللجنة المؤسسية على هاتف رقم 5300460 فرعي 1669.

### الجزء الثاني: تفويض من المشارك بالدراسة التي لا يتوقع منها فائدة مباشرة للمشارك:

اسم المشارك: -----

1. أقر و أنا في كامل أهليتي المعتبرة قانونياً بأنني قد قرأت - أو شرح لي بلغة مفهومة لدي - هذه المعلومات المتعلقة بمشاركتي في هذا البحث وأن (عبد الملك حسين) قد أوضح لي طبيعة وأهداف هذه الدراسة والانتزاعات, كما أقر بأنه قد أتاحت لي الفرصة لتوجيه جميع الأسئلة المتعلقة بموضوع الدراسة وتلقيت الإجابات الوافية.
2. أفهم بأن هذه الدراسة ليس لها أي فائدة علاجية مباشرة لي ومع ذلك أتطوع بالمشاركة فيها مع علمي بالمخاطر والانتزاعات الناتجة عنها.
3. وأفهم بأن لي مطلق الحرية بسحب هذا التفويض وإنهاء مشاركتي بهذه الدراسة في أي وقت أشاء مع علمي بجميع العواقب والمخاطر المترتبة على انسحابي من الدراسة (إن وجدت). كما أفهم بأن انسحابي من هذه الدراسة لن يؤثر على حقني في تلقي العناية الطبية اللازمة والتي تمنح للمشاركين بالدراسة أو استحقاقها في الأحوال العادية.
4. أوافق على أن يكون هذا الإقرار كمشاركة طوعيه في هذا البحث الطبي.
5. كما أؤكد بأنني قد قرأت (أو قرأ لي) هذا التفويض وأن كل المعلومات اللازمة قد تمت تعينتها بدقة قبل توقيع علي.
6. أقر بأنني قد استلمت نسخة موقعة من هذا الإقرار.
7. قد يقوم الباحث الرئيس بطرح بعض الأسئلة عليك بعد الانتهاء من شرح الإقرار.
8. بهذا أتطوع للمشاركة في هذه الدراسة تحت إشراف الدكتور جمال خضر , والمتضمن لما يلي: (دراسة تجربة سرطان البروستاتا عند المسلمين في الأردن)



إقرار بالموافقة على بحث بدون فائدة مباشرة للمشاركين

3

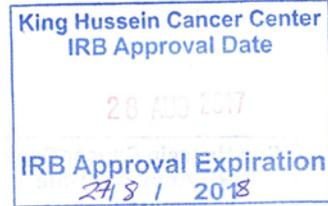
Informed Consent for Research with No Direct Benefits to Participant

توقيع المريض أو ولي الأمر: \_\_\_\_\_ التاريخ: \_\_\_\_\_  
الاسم \_\_\_\_\_ صلة القرابة \_\_\_\_\_  
توقيع الشاهد: \_\_\_\_\_ الاسم: \_\_\_\_\_  
الرقم الوطني: \_\_\_\_\_ التاريخ: \_\_\_\_\_

أقر بأنني قد شرحت للمتطوع/ أو ولي أمره المذكور أعلاه بصورة كاملة طبيعة وأهداف مشروع البحث المذكور والمتضمن عدم وجود فائدة مباشرة على المشارك. كما قد شرحت المضاعفات المحتملة حدوثها من جراء هذه الدراسة سواء كانت لأسباب معروفة أو غير معروفة. كما إنه من المفهوم لدي بأنه قد فهم طبيعة الدراسة والغرض منها والمخاطر الناتجة عنها وذلك قبل توقيعها على الموافقة بالمشاركة ، ولقد قمت بتوضيح استعدادي للإجابة على أي أسئلة متصلة بهذه الدراسة ، وقمت فعلاً بالإجابة الوافية على جميع أسئلته المتعلقة بالدراسة.

توقيع الباحث الرئيسي: \_\_\_\_\_ الاسم (طباعة): عبد الملك صالح حسنين حسنين  
التاريخ: 22/8/2017

تمت مراجعة هذا النموذج والموافقة عليه من قبل اللجنة المؤسسية في مركز الحسين للسرطان



إقرار بالموافقة على بحث بدون فائدة مباشرة للمشاركين

Informed Consent for Research with No Direct Benefits to Participant

## Appendix 7: Interview questions and technique



### Interview questions and technique

I will use the Biographical Narrative Interpretative Method (BNIM) interviewing technique to elicit an uninterrupted story from participants (Wengraf, 2001). I will start with one with a single question aimed at inducing narrative (SQUIN) which is **‘I would like to tell me your story with prostate cancer or please tell me about your experience of prostate cancer before diagnosis till now. I’ll listen first. I won’t interrupt you, I’ll just take some notes for afterwards’.**

After the participant finishes answering this question, I will present questions related to research questions to extract more details from the topics that emerged from his initial answer, such as:

- From your story, how has prostate cancer impacted on your life?
- What are the changes in your life that happened to you after having prostate cancer?
- How have you adapted to these changes?
- There are side effects come with prostate cancer and its treatments, have you had any, and if so, how have you dealt with them?
- How have these side effects impacted on your life?
- How does this experience impact on you as a man/your role as a man?
- What does manhood (masculinity) mean to you?
- How has prostate cancer impacted your own manhood?

Wengraf, T. (2001). Preparing Lightly-Structured Depth Interviews: A Design for a BNIM-Type Biographic-Narrative Interview. In *Qualitative Research Interviewing* (pp. 111-151): SAGE Publications, Ltd. Retrieved from <http://methods.sagepub.com/book/qualitative-research-interviewing>. doi:10.4135/9781849209717

## آلية المقابلة وأسئلتها

آلية المقابلة في هذه الدراسة تبدأ بسؤال واحد موجه للمشارك في الدراسة، السؤال هو: "أريد أن تخبرني عن قصتك مع سرطان البروستاتا أو عن تجربتك مع هذا السرطان من قبل التشخيص به إلى هذه اللحظة. سوف أستمع لك في البداية ولن أقاطعك، سوف أدون ملاحظات خلال إجابتك عن السؤال".

بعد أن ينتهي المشارك من الإجابة عن السؤال، سوف أسأله عدة أسئلة متعلقة بأسئلة البحث حتى أجمع تفاصيل أكثر عن الموضوعات التي طرحت من إجابته عن السؤال الأول.

الأسئلة تكون على النحو التالي:

- من قصتك، كيف أثر سرطان البروستاتا على حياتك؟
- ما هي التغييرات التي طرأت على حياتك بعد إصابتك بسرطان البروستاتا؟
- كيف تكيفت مع هذه التغييرات؟
- هناك آثار جانبية تأتي مع سرطان البروستاتا ومعالجته، هل كان لديك أي منها، وإذا كان الأمر كذلك، كيف تعاملت معها؟
- كيف أثرت هذه الآثار الجانبية على حياتك؟
- كيف أثرت هذه التجربة عليك كرجل / أو دورك كرجل؟
- ماذا تعني الرجولة (الذكورة) بالنسبة لك؟
- كيف أثر سرطان البروستاتا على رجولتك؟

الباحث الرئيسي: عبد الملك حسنين

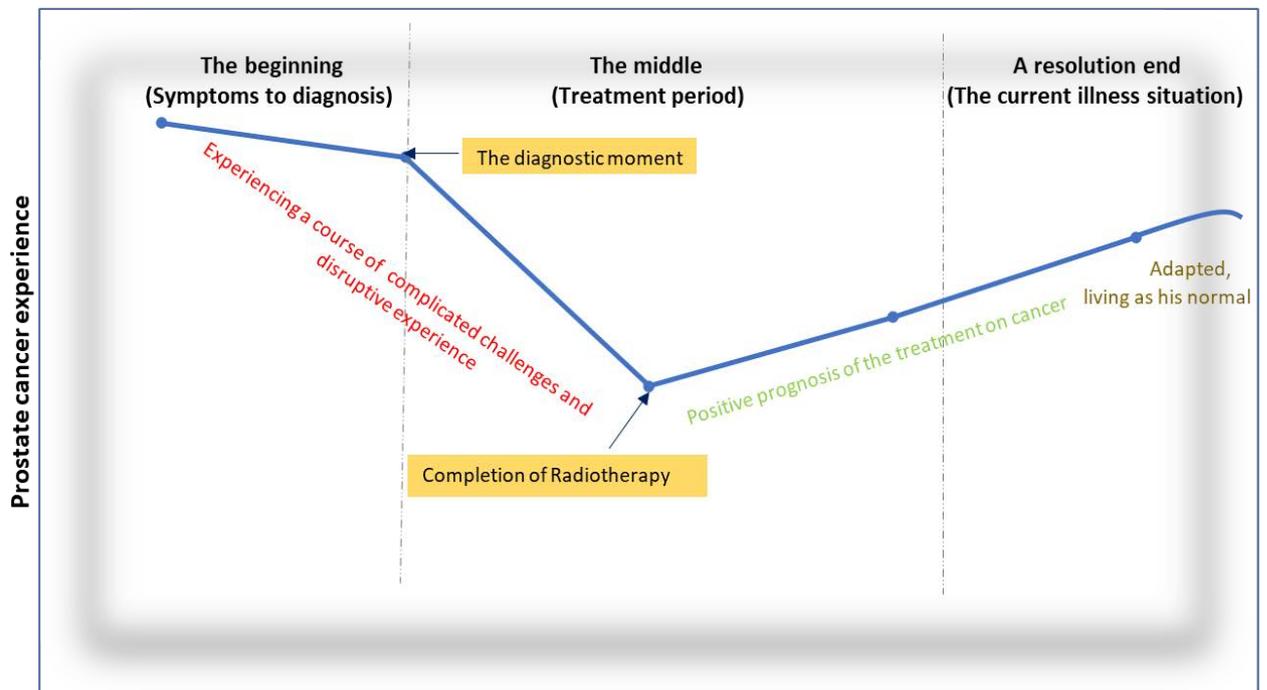
2017/2017

## **Appendix 8: Transcription conventions**

- (..) Silent interval
- ... Material omitted
- italic* Speaker emphasis
- [ ] My comments or participants' words that need to be explained
- (( )) Non-verbal activity or body gesture
- ? Mark up for question

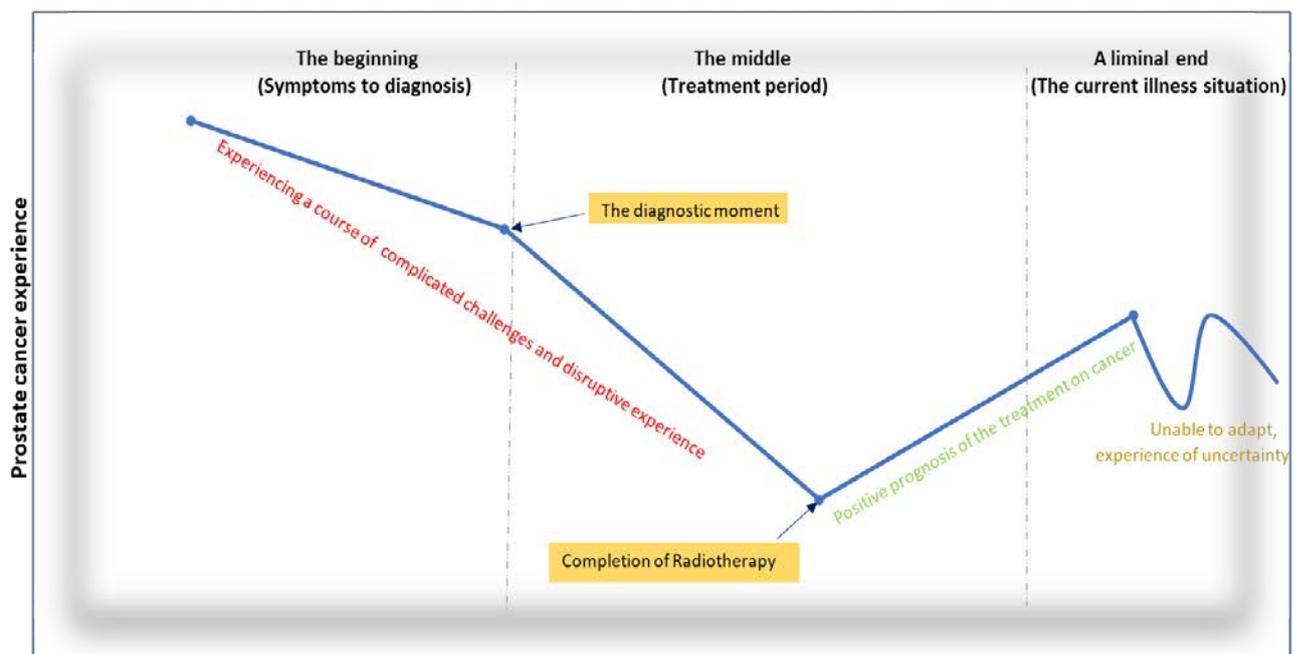
These transcription conventions are as outlined in the books of De Fina and Georgakopoulou (2019) and Wooffitt (2005), with minor modifications.

## Appendix 9: Graphs of the participants' story plots



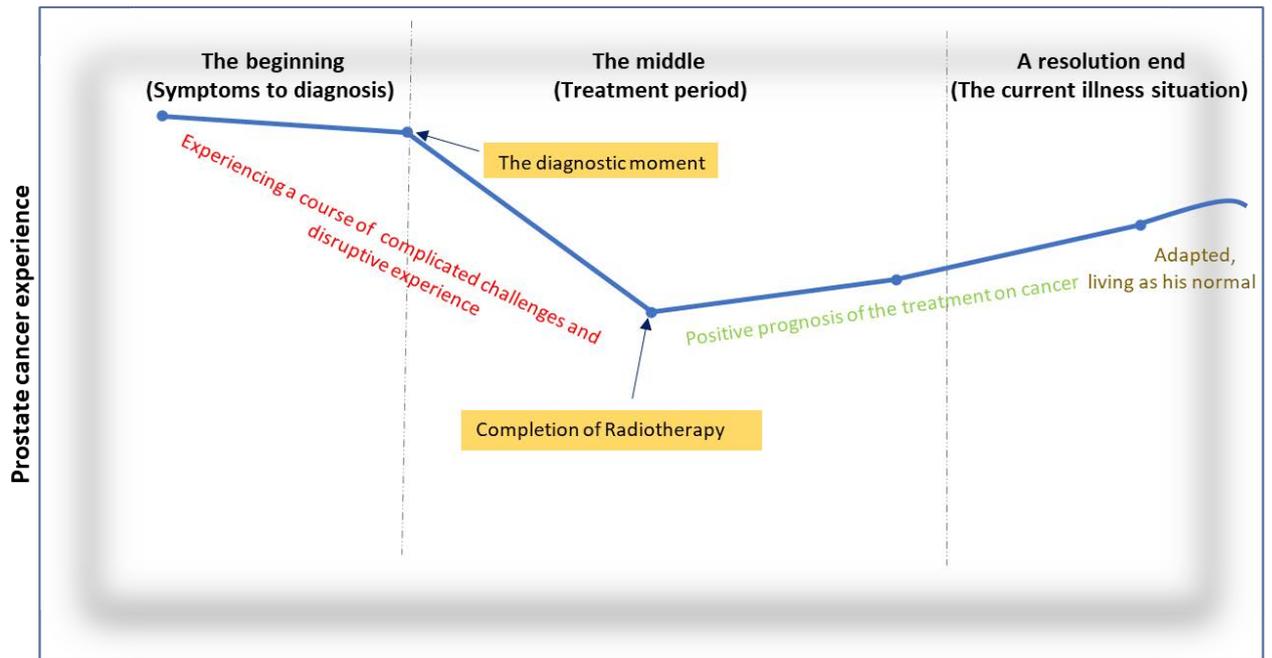
Prostate cancer storyline from pre-diagnosis to the current illness situation

—●— Participant 1's story plot



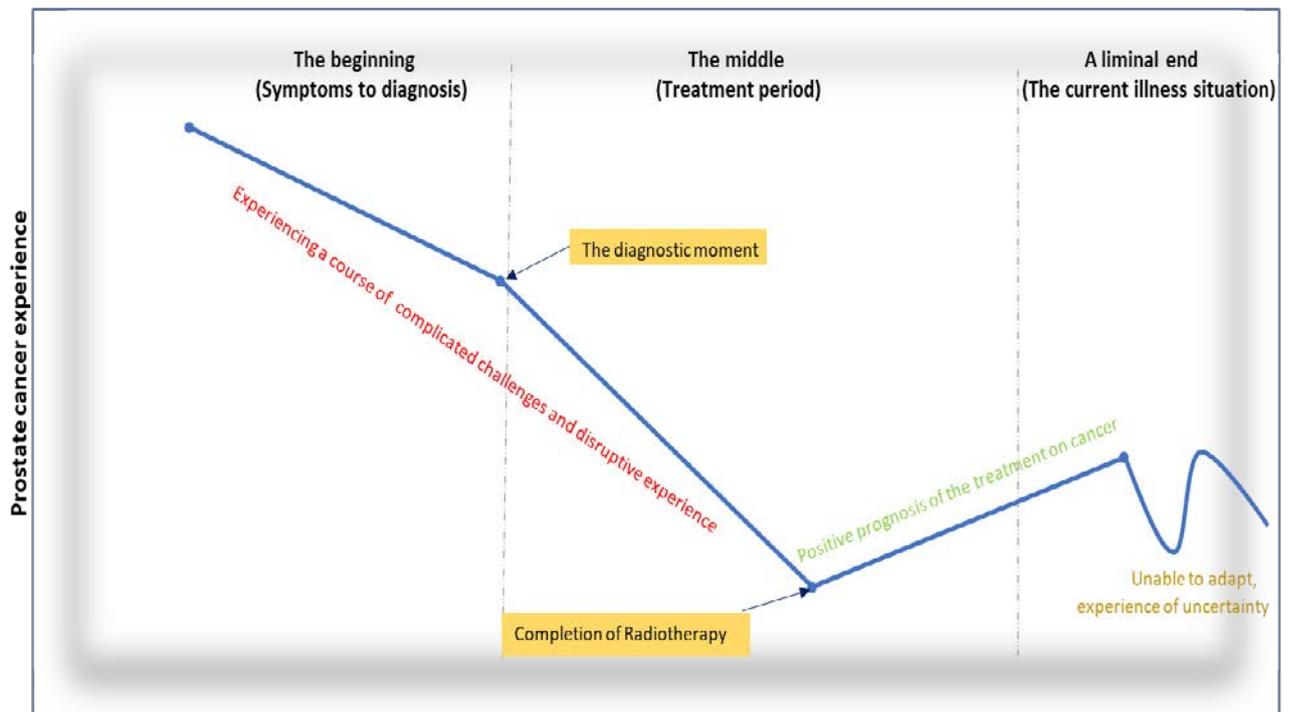
Prostate cancer storyline from pre-diagnosis to the current illness situation

—●— Participant 2's story plot



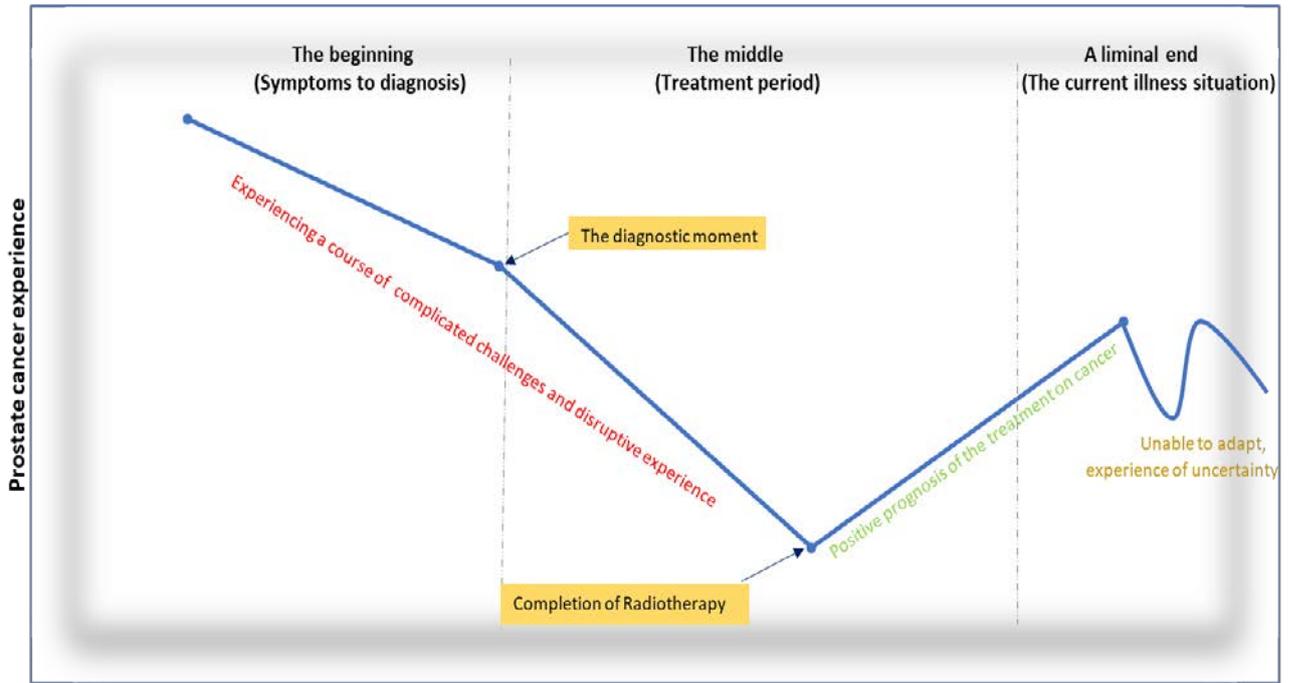
Prostate cancer storyline from pre-diagnosis to the current illness situation

—●— Participant 3's story plot



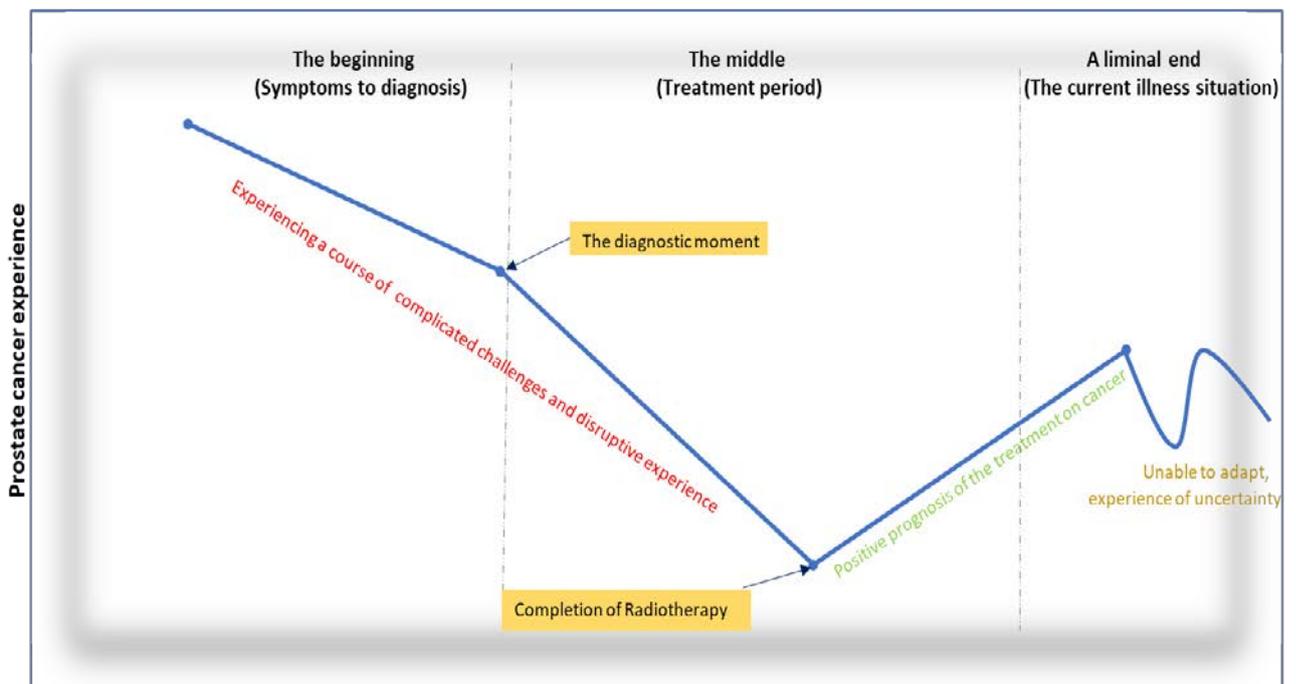
Prostate cancer storyline from pre-diagnosis to the current illness situation

—●— Participant 4's story plot



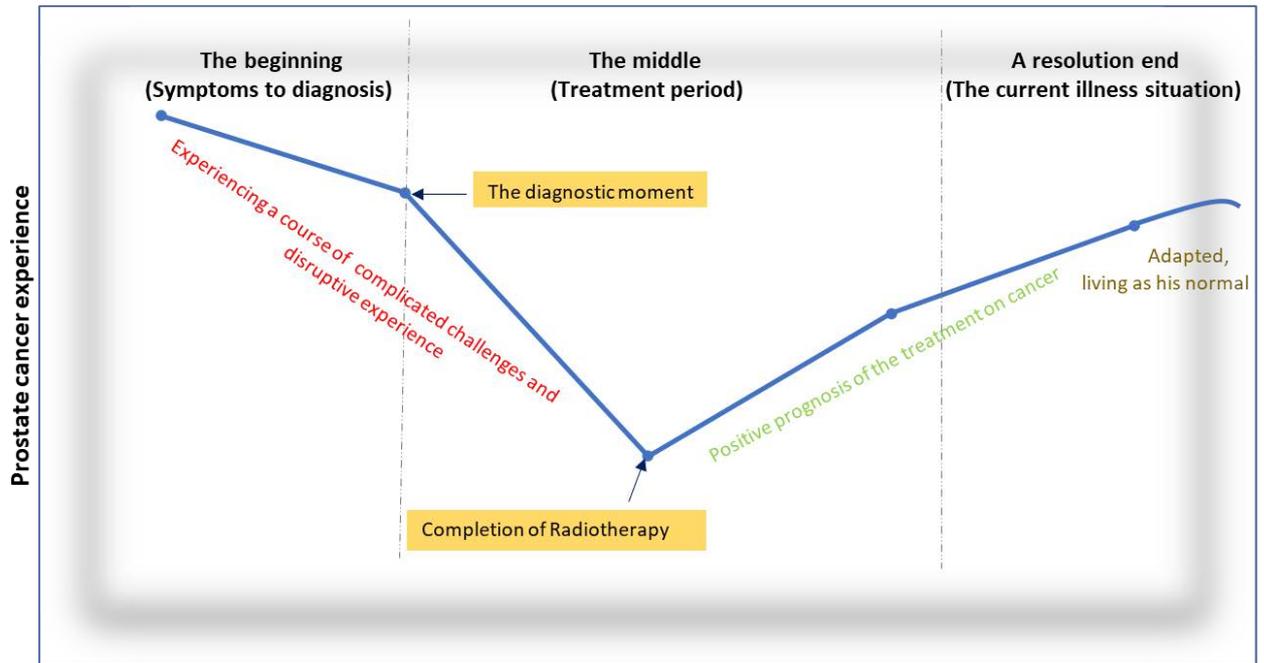
Prostate cancer storyline from pre-diagnosis to the current illness situation

Participant 5's story plot



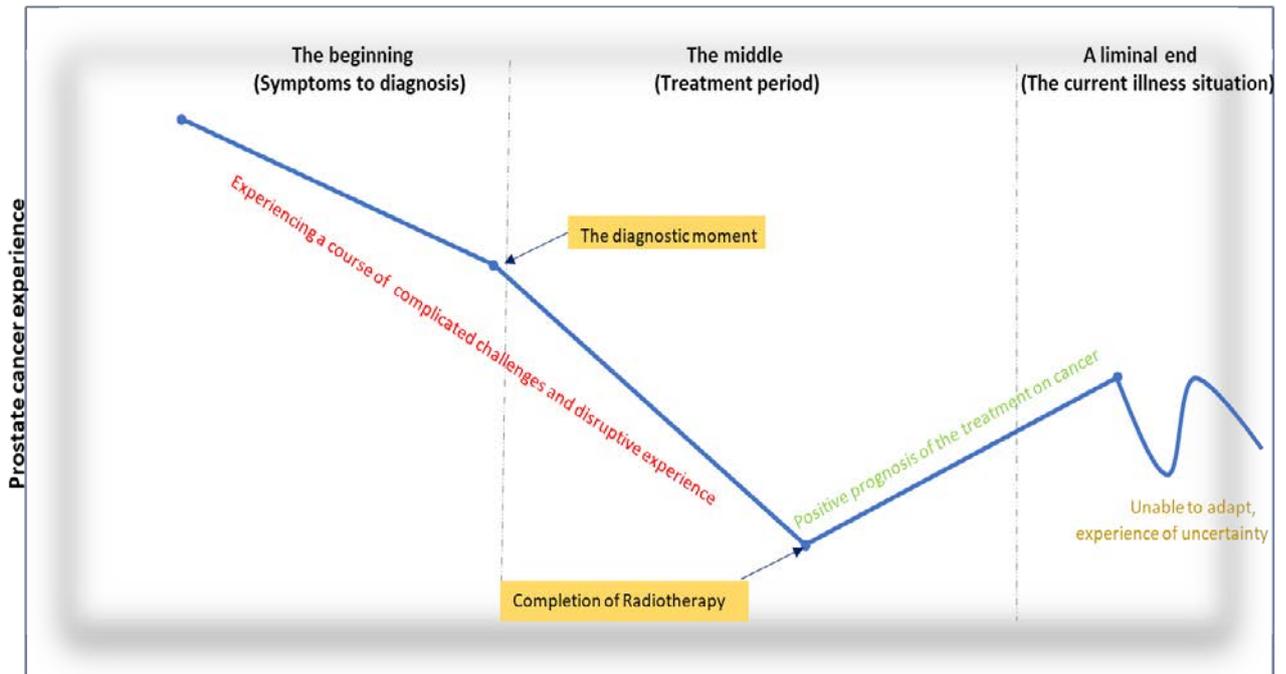
Prostate cancer storyline from pre-diagnosis to the current illness situation

Participant 6's story plot



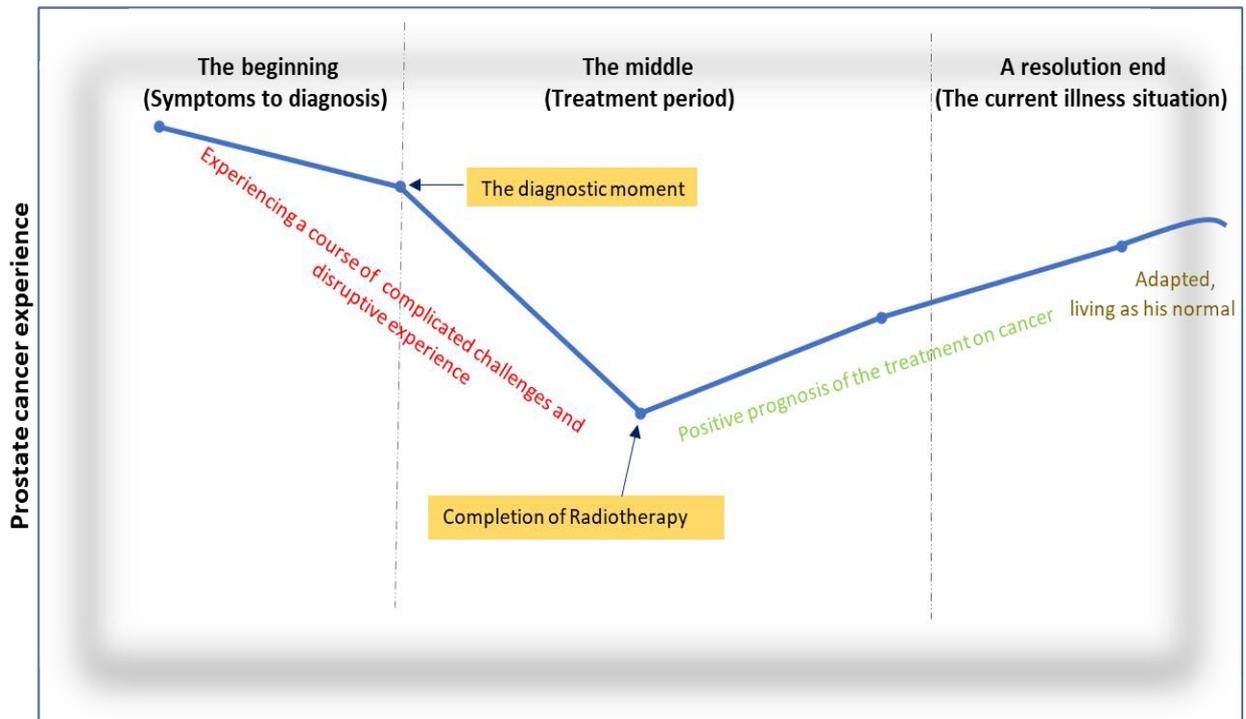
Prostate cancer storyline from pre-diagnosis to the current illness situation

—●— Participant 8's story plot



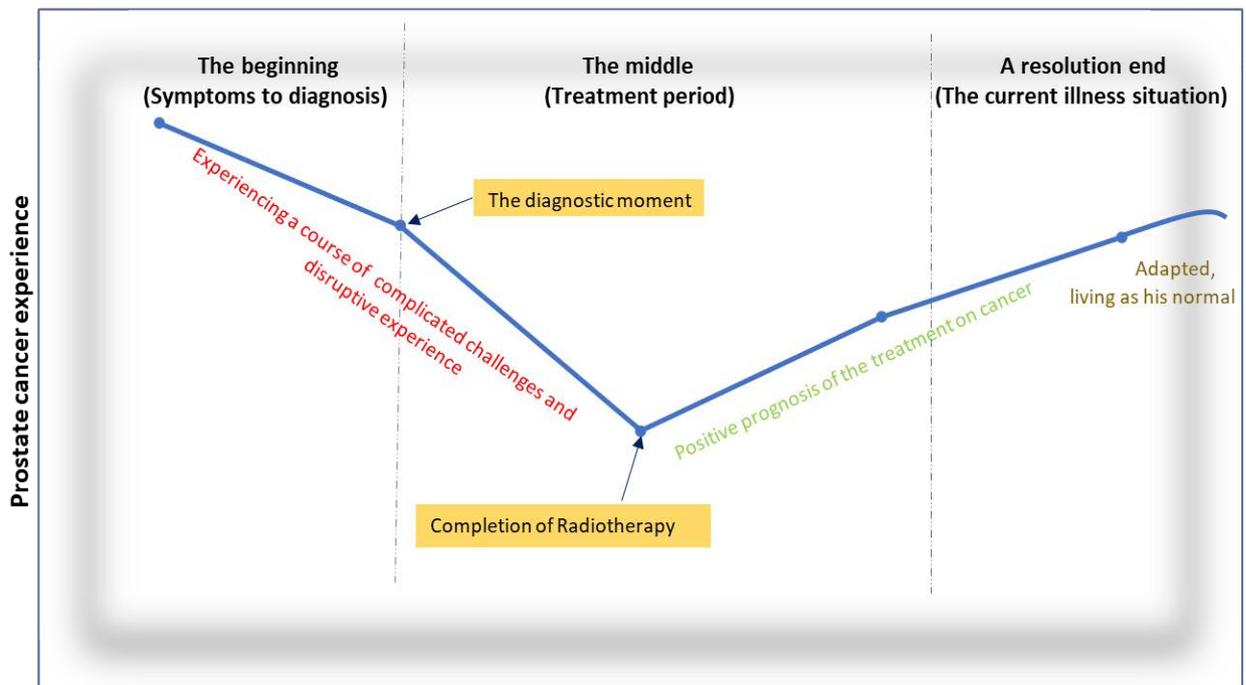
Prostate cancer storyline from pre-diagnosis to the current illness situation

—●— Participant 9's story plot



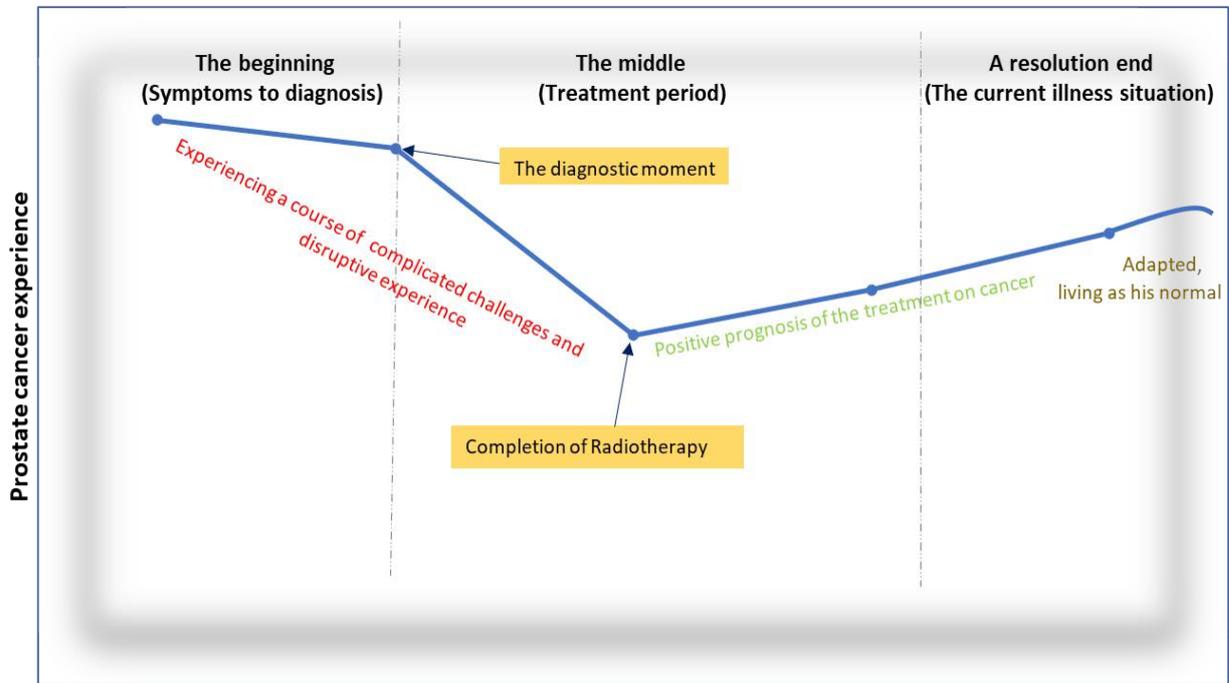
Prostate cancer storyline from pre-diagnosis to the current illness situation

Participant 10's story plot



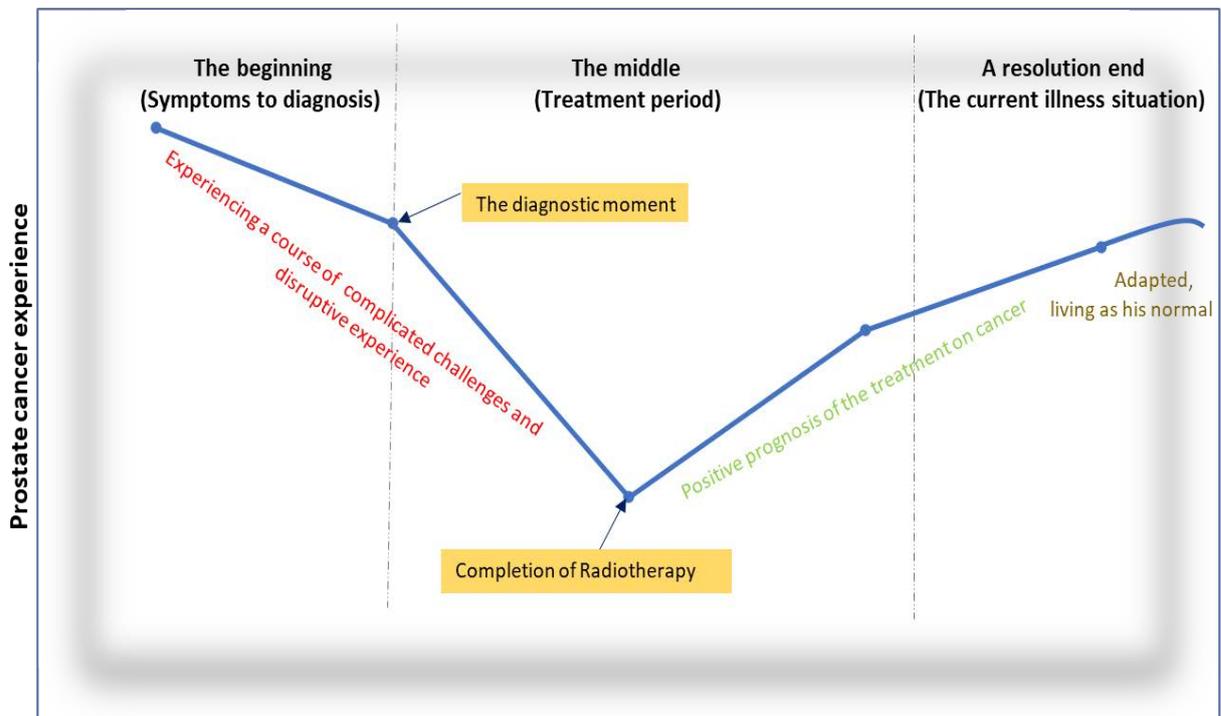
Prostate cancer storyline from pre-diagnosis to the current illness situation

Participant 11's story plot



Prostate cancer storyline from pre-diagnosis to the current illness situation

—●— Participant 12's story plot



Prostate cancer storyline from pre-diagnosis to the current illness situation

—●— Participant 13's story plot