Silence among Afro-Caribbean men diagnosed with prostate cancer in Trinidad and Tobago: A grounded theory study

By

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A thesis submitted for the degree of Doctor of Philosophy

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ABSTRACT

Silence among Afro-Caribbean men diagnosed with prostate cancer in Trinidad and Tobago: A grounded theory study

Background: Prostate cancer (PCa) is the leading cause of death among Afro-Caribbean men in Trinidad and Tobago (TT). TT is listed as one among countries with the highest PCa mortality rates in the world (Hosein et al., 2016). A systematic review undertaken explored men’s cultural beliefs about prostate symptoms and help-seeking behaviours, which revealed a dearth of knowledge of Afro-Caribbean men and PCa (King-Okoye et al., 2017). This study aims to explore men and partners’ experiences along care pathways for PCa in TT, including the beliefs and meanings men associate with their illness and its presentation.

Methods: Utilising Straussian grounded theory, semi-structured and focus group interviews were conducted with men (n= 51) diagnosed with PCa and partners (n=16) at four (urology & oncology) centres throughout TT in 2015-2016.

Results: Five categories: ‘Disrupting the Self’, ‘Disconnected to Health Services’, ‘The Silent Wall’, ‘Blame and Distrust’ and ‘Breaking the Silence’ and a core category, ‘Silence among Afro-Caribbean men’ (SAACM) were generated from the data. These connect with men’s late presentation of PCa at emergency services with severe and life-limiting symptoms associated with high mortality rates for this disease. The main reasons underlying men’s late presentation to health services with debilitating symptoms, concern masculinity norms, lack of awareness and knowledge of early stage PCa, cultural beliefs and practices and perceptions of an uncaring health system. These heavily influenced men’s ability to access care and move through routes to diagnosis for PCa in TT.
Conclusion: The SAACM offers unique insight into identifying how men’s cultural beliefs, hegemonic masculinity and lack of knowledge and awareness of the prostate and PCa resulted in delays in help-seeking and subsequently late diagnosis. A better understanding of men and their partners’ experiences along routes to diagnosis for PCa can target specific public health messages to address barriers to early diagnosis for men.

Key words: Trinidad and Tobago, experiences, beliefs, culture, silence
PUBLICATIONS


INTERNATIONAL CONFERENCE PRESENTATIONS


NATIONAL CONFERENCE PRESENTATIONS


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<tr>
<th>Acronym</th>
<th>Description</th>
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<tbody>
<tr>
<td>AS</td>
<td>Active surveillance</td>
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<tr>
<td>BME</td>
<td>Black Minority Ethnic</td>
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<tr>
<td>CABGS</td>
<td>Coronary Artery Bypass Grafts</td>
</tr>
<tr>
<td>CAP</td>
<td>Cluster Randomized Trial of PSA testing for PCa</td>
</tr>
<tr>
<td>CDAP</td>
<td>Chronic Disease Assistance Plan</td>
</tr>
<tr>
<td>CI</td>
<td>Confidence Interval</td>
</tr>
<tr>
<td>CIOS</td>
<td>Communication Institute for Online Scholarship</td>
</tr>
<tr>
<td>DH</td>
<td>Department of Health</td>
</tr>
<tr>
<td>DM</td>
<td>Diabetes Mellitus</td>
</tr>
<tr>
<td>EAU</td>
<td>European Association of Urology</td>
</tr>
<tr>
<td>DRE</td>
<td>Digital Rectal Examination</td>
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<tr>
<td>ERHA</td>
<td>Eastern Regional Health Authority</td>
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<tr>
<td>ERPSC</td>
<td>European Randomized Study of Screening for PCa</td>
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<tr>
<td>EWMSC</td>
<td>Eric Williams Medical Sciences Complex</td>
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<tr>
<td>FPATT</td>
<td>Family Planning Association of Trinidad and Tobago</td>
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<tr>
<td>GP</td>
<td>General Practice</td>
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<tr>
<td>GT</td>
<td>Grounded Theory Methodology</td>
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<td>HCP</td>
<td>Health Care Provider</td>
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<td>HR</td>
<td>Hazard Ratio</td>
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<td>HTN</td>
<td>Hypertension</td>
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<tr>
<td>MOH</td>
<td>Ministry of Health</td>
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<tr>
<td>NCRHA</td>
<td>North Central Regional Health Authority</td>
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<td>National Health Service</td>
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<td>National Radiotherapy Centre</td>
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<td>North West Regional Health Authority</td>
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<tr>
<td>PAHO</td>
<td>Pan American Health Organization</td>
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<tr>
<td>PCa</td>
<td>Prostate Cancer</td>
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<tr>
<td>PLCO</td>
<td>Prostate, Lung, Colorectal, Ovarian</td>
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<tr>
<td>POSGH</td>
<td>Port of Spain General Hospital</td>
</tr>
<tr>
<td>Abbreviation</td>
<td>Full Form</td>
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<tr>
<td>PRISMA</td>
<td>Preferred Reporting Items for Systematic Reviews and Meta-Analyses</td>
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<tr>
<td>PSA</td>
<td>Prostate Specific Antigen</td>
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<tr>
<td>RCT</td>
<td>Randomized Control Trial</td>
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<td>RHA</td>
<td>Regional Health Authority</td>
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<tr>
<td>RR</td>
<td>Relative Risk</td>
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<td>SATD</td>
<td>Scholarship and Advanced Training Division</td>
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<td>San Fernando General Hospital</td>
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<td>Symbolic Interactionism</td>
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<td>South West Regional Health Authority</td>
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<td>S3M</td>
<td>Stockholm-3 Model</td>
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<td>UWI</td>
<td>University of the West Indies</td>
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<td>TRHA</td>
<td>Tobago Regional Health Authority</td>
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<tr>
<td>TRANS</td>
<td>Trans-rectal ultrasound</td>
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<tr>
<td>TURP</td>
<td>Trans-urethral resection of the prostate</td>
</tr>
<tr>
<td>TT</td>
<td>Trinidad and Tobago</td>
</tr>
<tr>
<td>TTCS</td>
<td>Trinidad and Tobago Cancer Society</td>
</tr>
<tr>
<td>UK</td>
<td>United Kingdom</td>
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<tr>
<td>USA</td>
<td>United States of America</td>
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<tr>
<td>USPSTF</td>
<td>U.S Preventive Services Task Force</td>
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<td>WHO</td>
<td>World Health Organization</td>
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CHAPTER ONE - INTRODUCTION

The purpose of this chapter is threefold. Firstly, it describes the background to the study. Secondly, it outlines my personal and professional interest towards conducting the study. And thirdly, it guides the reader to the rest of the thesis and provides an overview of the culture and geography of Trinidad and Tobago (TT). These provide the context through which the study is based.

1.1 Background to the Study

Prostate Cancer (PCa) is the leading cause of death among men in TT (Ramkissoon & Goetz, 2014). This twin isle has been listed as one country (44.0% deaths/100,000) with the highest PCa mortality rates in the world (Hosein et al., 2016; Torre et al., 2015; Warner et al., 2018). TT is followed by U.S Blacks (25.3% deaths/100,000), Cuba (23.5% deaths/100,000) and South Africa (22.4% deaths/100,000) with the lowest incidence and mortality rates reported in Asia (Mutetwa et al., 2010) (see Figure 1). Variations in incidence and mortality rates reflect genetic susceptibility, limited access to healthcare and use of prostate-specific antigen (PSA) testing (Center et al., 2012; Mutetwa et al., 2010; Rebbeck et al., 2013). A retrospective clinical pathological study utilising trans-rectal ultrasound (TRUS) guided biopsy was conducted among 546 men over 30 months at one tertiary referral centre in South Trinidad. This showed that Afro-Trinidadian men were more likely to present with poorly differentiated and aggressive: D’Amico high-risk tumours (D’Amico et al., 1998) and perineural invasion than their Indo-Trinidadian counterparts (Hosein et al., 2016). The increasing mortality rates coupled with a four-fold risk of death (Hazard Ratio (HR): 3.58; 95% Confidence Interval (CI)= 2.23-5.73) for TT born men (Mutetwa et al., 2010) are a priority area for health services as men of African ethnicity have a higher risk of developing PCa than any other ethnic group (Anderson & Marshall-Lucette, 2016; Ramkissoon & Goetz, 2014; Thakare & Chinegwundoh, 2015; Warner et al., 2018; Williams, 2014). Moreover, men of African ethnicity reflect 95% of the male population of Tobago and 45% of that of Trinidad (Central Statistical Office of TT, 2016). Reports from the National Cancer Registry of TT (1997-2006) have also shown that men were diagnosed at advanced stages of PCa (Mungrue et al., 2012; Mutetwa et al., 2010; Ragin et al. 2007). Although there are no studies that have specified the symptoms TT men present with, we know from other studies that men presenting with late-stage disease have identified debilitating pain with pathological fractures and urinary retention as advanced symptoms of PCa (Drudge-Coates et al., 2018; Patrick et al., 2015).
Prostate screening via PSA and digital rectal examination (DRE) is not routinely offered in TT. This may be due to an absence of a ‘clearly articulated policy on PCa screening in TT’ (Ocho & Green, 2013, p. 187). Additionally, there are different groups of men participating in clinical trials and varied guidelines for screening and treatment of PCa throughout health services in TT. For example, Tobago has ongoing PCa screening studies and clinical trials that commenced in 1997 in collaboration with Pittsburgh University, USA, that justifies population-based screening in men aged 40-69 years with the goal of reducing PCa mortality rates (Patrick et al., 2010; 2015; 2016). Whereas Trinidad has no known ongoing PCa clinical trials and screening studies (United Nations Population Fund, 2011) and therefore PCa screening is not provided routinely to men (Ocho & Green, 2013). Active surveillance (AS) is advocated for symptomatic men at some health services (Persuad et al., 2017). However, the PSA and DRE tests are offered at selected private and public health systems throughout TT, based on men’s expressed needs (Ocho & Green, 2013). The PSA and DRE tests are provided at a subsidized cost (TT$180/150 respectively) to men over 40 years of age (TT Cancer Society (TTCS), 2017; 2018), whilst these may be freely accessed at no cost through some employers and public health systems (Family Planning Association of TT (FPATT), 2013). However, men at 40 years and over are the recommended age for PCa screening at most health services in TT (TTCS, 2017; Ministry of Health (MOH), 2016).

The lack of standardization in TT surrounding population-based screening may be linked with controversies surrounding benefits and harms of PSA screening in the research literature. The U.S Preventive Services Task Force (USPSTF) found that there was insufficient evidence to recommend for or against PSA and DRE screening (1989, 2002). Following this, the USPSTF (2008) concluded (Grade D recommendation) that the evidence of the benefits versus the harms of PSA and DRE were insufficient for men younger than age 75 years. However, this recommendation opposed screening for men older than 75 years due to harms outweighing the benefits of screening for these men. Some prostate-related screening harms identified were discomfort from prostate biopsies, false-positive tests and the psychological reactions connected to these; and treatment-related complications such as erectile and bowel dysfunction, urinary incontinence and death (Moyer et al., 2012). These guidelines were based on evaluations of randomized controlled trials (RCTs) of benefits of PSA screening, and cross-sectional and cohort studies that showed psychological harm of false-positive PSA test results and over diagnosis of slow-growing PCa that may not affect men during their lifetime (Moyer et al., 2012). The USPSTF then recommended ‘no screening’ policy to men of all ages due to insufficient evidence of health benefits (USPSTF, 2012; Schröder et al., 2012).
Additional evidence from ongoing clinical trials as stated in USPSTF (2017) draft report showed a reduction in PCa mortality rates, prevention of metastatic PCAs and the inclusion of AS which reduced treatment-related harms. Hence, current USPSTF ‘Grade C’ recommendations advocate for individualized informed screening in men age 55-69 years and high-risk populations, which are men of African ethnicity and a family history of PCAs.

Figure 1. The cancer profile for TT adapted from the World Health Organisation (WHO) Cancer Country Profiles (2014)
The American Prostate, Lung, Colorectal and Ovarian Cancer Screening Trial (PLCO) (n=76, 693) found no significance in mortality rates (Relative Risk: RR) = 1.13, 95% Confidence Interval: 0.75–1.70) in screening among men aged 55-74 years that received PSA over a course of 6 years and DRE screening for 4 years in comparison to men in the control group. However, cancers were detected in men that received routine PSA screening (RR = 1.22, 95% CI: 1.16–1.29) compared to men in the control group (Andriole et al., 2012). Conversely, the European Randomized Study of Screening for PCa (ERSPC) found that PSA screening reduced mortality rates for PCa after a long-term follow-up of 13 years (Schröder et al., 2014).

Similarly, current UK and European policy do not support national-based screening for PCa. However, these policies advocate the use of PSA screening for high-risk men as the USPSTF policy. The UK Policy Position statement (2016) identifies the PSA test as the best means of achieving early detection of PCa in asymptomatic men. This position is based on results of a meta-synthesis involving five RCTs: PLCO, ERSPC (already discussed) and Norrkoping, Quebec and Stockholm (European Association of Urology (EAU), 2012; Ilic et al., 2013; Heidenreich et al. 2013). Even though these studies had differing screening methodologies, design, thresholds, frequencies and analysis, this meta-analysis concluded that screening was not significant towards reducing PCa-specific mortality (Ilic et al., 2013).

The most current evidence from a cluster randomized clinical trial (The Cluster Randomized Trial of PSA testing for PCa (CAP)) that examined the usefulness of PSA in reducing PCa mortality rates have also supported UK policy towards non-population-based screening for PCa (Martin et al., 2018). This trial involved over 400, 000 men aged 50-69 from 600 General Practice (GP) in the UK that ran over 10 years. In the intervention group a PSA test was done upon invitation whereas the control group followed standard practice (no PSA offered). The CAP trial detected many low-risks PCa among men that were offered a single PSA test. However, there were no significant differences in PCa mortality in comparison to men that did not attend PSA screening. The CAP trial concluded that a single PSA test in asymptomatic men is not beneficial since low-risk PCa may not necessarily further develop or cause harm and aggressive PCa may have been missed and not treated in a timely manner (Martin et al., 2018). However, some limitations were identified in the CAP trial. The researchers noted that a single PSA test is unsuitable to reflect PSA trends as seen in the previous ERSPC and PLCO clinical trials. They concluded that the CAP trial was not sufficiently powered to examine screening in men at higher risk for PCa. Hence, incident and lethal PCas were under detected. A lower adherence rate (40%) in the intervention group was found in comparison to the
other trials (ERPSC: 59% -69%), which may reflect inconsistencies in findings. They considered that follow-up over 10 years may have been too short to accurately assess the effects of PSA screening and post-randomization exclusions may have potential to lead to bias (Martin et al., 2018).

The Stockholm-3 Model for PCa detection appears promising as a screening tool for PCa that would replace PSA testing (Grönberg et al., 2015). The overall goal of the Stockholm-3 Model is to minimize biopsies conducted; find aggressive cancers faster and avoid detection of clinically insignificant cancers. In a prospective, population-based diagnostic study, PSA blood samples were taken from 47,000 men in Stockholm, Sweden aged 50-69 years that were not diagnosed with PCa. Blood samples above 1ng/ml were screened through the S3M test panel, which consisted of genetic and protein biomarkers that are more sensitive to identifying clinically significant PCas than the PSA blood test. A PSA blood sample score of 3ng/ml or more is considered high risk for PCa. Hence men were referred for a DRE. If suspicious for cancer, this was followed by a biopsy and prostate volume tests. Only 4,947 men were biopsied which were representative of 32% decrease in the number of biopsies performed. Even though this evidence can reduce unnecessary biopsies, improve PCa risk assessment and avoid over diagnosis of PCa, there were a few limitations. This study was conducted in Stockholm and may not reflect the diversity of men compared to other countries. The cost of S3M test panel for larger populations must be considered in relation to cost-effectiveness. Also, the samples were examined by a single pathologist, which does not represent an ideal clinic setting. However, a feasibility test conducted among 56,282 men from the PSA and biopsy registry of the Stockholm population demonstrated its usefulness towards replacing current clinical practice (Eklund et al., 2016). The Stockholm-3 Model might be useful for high-risk populations such as TT, as it includes personal risk factors and weighs the PSA scores hence the genetic and protein biomarkers could be useful for Afro-Caribbean men. This is free-PSA which is more sensitive in detecting PCas. It is the future but most probably will be costly and not available in TT for some years, hence the need to focus on routes to diagnosis as an adjunct to these new tests becoming available in the future.

While there has been considerable research globally on the usefulness and harms of screening (Andriole et al., 2012; Schröder et al., 2009; 2014) and the general impact of PCa on the health and well-being of men and their families (Mellon & Northouse, 2001; Boehmer & Clark, 2001b; Maliski et al., 2001), there remain critical gaps in the research evidence base on men’s beliefs and factors that impinge on their ability to access healthcare. A recent scoping study that utilised a symbolic interactionism (SI) approach found that beliefs surrounding culture among Black men were related
to personal, structural and societal factors (Machirori et al., 2018). Personal factors were linked to health practices and PCa disease; structural factors were connected to relationships and access to information, health focus and medical treatment cost whilst social factors were associated with language, health practices and PCa practices (Machirori et al., 2018).

However, the role of culture surrounding men’s beliefs and perceptions along routes to diagnosis for PCa remains under researched for the TT population. This is also inclusive of how men experience routes to diagnosis for PCa and factors that impact their access and adherence to treatment. Higher prostate screening uptake among Afro-Caribbean populations might prove beneficial towards an early diagnosis and early treatment for PCa considering the evidence. However, Afro-Caribbean men’s reluctance to access these services at the recommended age have been well documented (Aiken & Eldemire-Shearer, 2012; Jemal et al., 2012; Bourne et al., 2010; Ocho & Green, 2013). Some reasons highlighted for men’s reluctance were fear of a diagnosis of cancer and homophobia in relation to the DRE test. However, findings related to TT men’s reluctance represent those that were not diagnosed with PCa (Ocho & Green, 2013). Due to the low level of symptoms of early stage PCa (Cancer Research UK, 2015a), it is important to examine perceptions and meanings of symptoms among men recently diagnosed with PCa in TT so that the relationship to help-seeking can be explored in routes to diagnosis and treatment. Additionally, there is a dearth of information about their partners’ role along the journey to diagnosis and treatment in TT. This research study investigated beliefs of men newly diagnosed with PCa and their partners along their journey to diagnosis and treatment and the role and impact their partners played towards PCa detection in TT.

1.2 Focus of the Study

Routes to diagnosis have been the subject of interest for public health research for decades (Andersen et al., 1995; Scott et al., 2013; Walter et al., 2012). Finding the right framework for routes to diagnosis has been significant towards understanding the behavioural and decisional processes that guide individuals through diagnosis to treatment. ‘Routes to diagnoses’ are defined as the route a patient follows to the point of diagnosis (Public Health England, 2010).

The revised Andersen model of total patient delays (Andersen et al., 1995; Walter et al., 2012) highlights a systematic outline of events, processes and intervals that may occur along routes to diagnosis (see Figure 2). It identifies five key events, four processes along four intervals, with broad
contextual factors that may impinge on individuals’ journey through diagnosis and treatment of any disease. These five events are: detection of bodily change, perceives reason to discuss symptoms with Health Care Provider (HCP), Diagnosis and Start of Treatment. The processes highlighted in this model are: patient appraisal and self-management, decision to consult HCP and arrange appointment, HCP appraisal, investigations, referrals and appointments and planning and scheduling of treatment. The intervals listed are: Appraisal, Help-seeking, Diagnostic and Pre-treatment. And lastly, contributing factors are patient, healthcare and system and disease factors (Scott et al., 2013; Walter et al., 2012).

Figure 2. The revised Andersen's model of total patient delay (taken from Walter et al., 2012, p. 116)

An examination of routes to diagnosis highlights delays that patients may encounter. The revised Andersen model of total patient delay has clearly identifiable stages from the recognition of symptoms to presentation at an HCP, diagnosis and start of treatment (Scott et al., 2013; Walter et al., 2012). These will be discussed in context to appraisal delay, help-seeking delay, diagnostic delay and pre-treatment and treatment delays.

Appraisal delay or ‘symptom appraisal’ is defined as the time from the onset of the symptom to the recognition of seriousness and seeking help from a medical doctor (Scott et al., 2013; Walter et al., 2012). The nature of symptoms experienced is highlighted as the most important factor for appraisal delay. Patients that recognise red-flag symptoms experience shorter delays than those that attribute symptoms to normality. However, low levels of anxiety, non-recognition, misattribution and misinterpretation of symptoms are also noted as barriers to the appraisal process. Self-management is seen as a major barrier that occurs during the appraisal interval. This
is inclusive of self-monitoring, self-medication, seeking non-medical advice and adaptations to lifestyle. The cultural and social context of symptoms experienced, including the role of social capital are considered highly relevant during the appraisal of symptoms (Scott et al., 2013; Walter et al., 2012). Help-seeking delay or ‘time to presentation’ is defined as the time taken from perceiving a reason to seek medical help to the first consultation with an HCP (Scott et al, 2013; Walter et al., 2012). Factors such as competing events, expectations about seeking medical care and emotions have been said to impede decisions to help-seeking. Other issues such as accessibility and availability of HCPs and scheduling of appointments at health systems are potential barriers to help-seeking (Scott et al., 2013; Walter et al., 2012). Diagnostic delay or time to diagnosis is defined as the time from the first meeting with an HCP to a formal diagnosis (Scott et al, 2013; Walter et al., 2012). Some potential barriers that occur during the diagnosis interval are misdiagnosis, dismissal of symptoms or no diagnosis being made and lack of safety-netting for patients (see page 202) (Scott et al, 2013; Walter et al., 2012). Pre-treatment and treatment delays or time to treatment refer to the time from a formal diagnosis to the start of treatment (Scott et al., 2013; Walter et al., 2012). These mainly rely on HCPs expertise towards treatment decisions and system factors that would enable a smooth transition through primary and secondary care. Non-investigation of symptoms and treatment of non-related causes are highlighted as delays caused by HCPs, whereas lack of availability of treatment and lack of follow up care and referral delays connect to system delays (Scott et al., 2013; Walter et al., 2012).

The Andersen (1995) model of total patient delay encompasses existing psychological theories such as Leventhal (Leventhal & Crouch, 1997) Common Sense Model of Illness Self-regulation and Bandura (1977) Social Cognitive Theory as theoretical foundations underpinning the Appraisal and Help-seeking intervals. As the focus of the study is to examine the experiences of men newly diagnosed with PCa and their partners in TT, it is essential to look at this in context of routes to diagnosis for PCa. As highlighted in the revised Andersen’s model (Walter et al., 2012) this can identify events, processes, intervals and contributing factors relevant to men and partners’ experiences. However, this is used as a broad guide in relation to interview questions with flexibility during data collection.

1.3 Personal Interest in the Study

As a female Afro-Caribbean of mixed heritage (Amerindian, Chinese, Hispanic and African), I was born and raised in Trinidad and obtained clinical experience in the field of critical care, emergency care, postoperative care and oncology. I am interested in ethnicity and cancer and public health
implications. My postgraduate training mainly comprised of taught and research modules from McMasters University, Canada and The University of Surrey, United Kingdom; and practical experience from the former university. I had been working as a full-time lecturer at The University of the West Indies (UWI), Trinidad, with international collaboration with Mount Vernon Cancer Centre, Imperial College Hospital and Royal Marsden, UK whereby I supervised oncology nurses’ clinical observer ship. This experience motivated my personal interest towards cancer research. I specifically desired to contribute to the field of knowledge for Black Minority Ethnic (BME) groups within TT, the Caribbean and internationally due to their disproportionate representation in clinical trials and cancer research. The Scholarship and Advanced Training Division (SATD), Ministry of Public Administration, TT provided funding for this. My vision was to better understand cancer care that would enable me to provide innovative public health interventions to improve the outcomes for men with PCa. After completing my Master of Science degree in cancer care at The University of Surrey, UK, my vision was refocused to gaining insights into Afro-Caribbean men and partners’ PCa experiences considering the alarming incidence and mortality rates in TT. Professor Sara Faithfull and Dr Anne Arber inspired this vision. The proposal was well received and supported by SATD within the Education division.

1.4 A Guide to the Rest of the Thesis

This chapter provides the background and focus of the current study in relation to men and their partners’ PCa experiences. It has outlined my personal and professional interest in the current study. It continues to outline the nation of TT in context to culture, geography, healthcare and politics, which sets the tone for the rest of the chapters (see Figure 3).
CHAPTER 1
BACKGROUND & CONTEXT

CHAPTER 2
REVIEW OF LITERATURE

PART One: Systematic Review (Published): Men’s beliefs & help-seeking actions for prostate symptoms
PART Two: Literature Review: Men and partners’ experiences of prostate cancer
PART Three: Theoretical Literature Review

CHAPTER 3
Research Paradigms & Research Methodology

CHAPTER 4
Research Design, Procedures & Methods

FINDINGS CHAPTERS

CHAPTER 5
TT men & partners accounts of pre-diagnosis experiences

CHAPTER 6
TT men & partners accounts of diagnosis and post-diagnosis experiences

CHAPTER 7
Substantive theory
Discussions
Contributions to research, Recommendations & Implications to practice

Figure 3: The structure of this thesis
After setting the tone for the study, to explore men and partners’ experiences of PCa, chapter two provides a review of empirical and theoretical literature. As Straussian grounded theory emphasizes the use of the literature at all stages of the research process, it was important to gain insight into gaps within PCa and relevant literature (Corbin & Strauss, 2015). Hence this review is divided into three parts. The first part presents a systematic review of literature that explored men’s routes to diagnosis of PCa with specific foci on men’s cultural beliefs and how their symptoms experienced affected help-seeking behaviours (King-Okoye et al., 2017). This part also highlights gaps in PCa literature such as a dearth of studies exploring men’s cultural beliefs about prostate symptoms and how these influenced their appraisal of symptoms and help-seeking behaviours. The second part presents a review of studies on men and partners’ experiences of PCa, which takes a broader perspective of their accounts of diagnosis, treatment and follow up care. The third part highlights theoretical literature that underpins key concepts identified in the combined review of literature. These are lay beliefs, culture and symptoms and masculinity as it pertains to men with PCa. These concepts draw on a range of theoretical frameworks. Bury’s (1982) framework of biographical disruption, Radley’s (1994; 1996; 1999) framework of illness representation and masculinity as theorized by Connell (2005) and Kelly (2004, 2009) are discussed in this chapter. The identified gaps and theoretical frameworks offer a holistic and comprehensive insight into men and partners’ experiences of PCa through the following research questions: What are newly diagnosed men and their partners’ beliefs, about their illness, along their journey to diagnosis and treatment for PCa in TT? How do men and their partners experience routes to diagnosis for PCa in TT? Why do men access healthcare services late in TT? What are the differences between the experiences of men and their partners in the two islands of TT? The literature review was integrated into the analysis (chapters 5 and 6) and discussion (chapter 7) in accordance to the principles of Straussian grounded theory methodology (GT) (Corbin & Strauss, 2008).

After being sensitized through the literature, chapters 3 and 4 discuss the methods and methodology utilised in accordance with the aims and objective of the study. In chapter 3, I provide a discussion and justification for the selected research paradigm of interpretivism. I also provide the basis through which Straussian GT (Corbin & Strauss, 2008) was selected as most appropriate to answer the research questions generated from the review of empirical and theoretical literature. I was interested in the social processes and actions surrounding men and their partners’ experiences of PCa along routes to diagnosis in TT. These are men’s appraisal responses, help-
seeking behaviours, factors underlying their late presentation and delayed access to health services and experiences of debilitating symptoms and late diagnosis.

Chapter 4 describes the research design, procedures and methods employed in this study. This relates to data collection procedures, tools and methods and data analysis following Straussian GT (Corbin & Strauss, 2008). The rationale for these design, tools and methods are provided. A total of 51 men and 16 partners participated in the study in August-September 2015 (Tobago) and April-May 2016 (Trinidad) and completed face-to-face interviews. Based on my ethnicity, nationality and work experience (discussed in 1.3), I brought to the study my own beliefs, preconceived biases, background knowledge and experiences and assumptions that could have influenced the research process. Through reflexivity and expert supervisory guidance, methodological rigor was achieved. Hence, I provide an audit trail of the research trajectory throughout the thesis.

The categories derived through analysis of data utilising Straussian Grounded Theory (Corbin & Strauss, 2008) are extensively discussed in chapters 5 and 6. Chapter 5 discusses participants’ pre-diagnosis journey. The categories highlighted here are, ‘Disrupting the self’ and ‘Disconnected to health services’. These identify men and partners’ appraisal and help-seeking experiences for prostate health. Chapter 6 describes participants’ diagnosis and post-diagnosis journey. The categories highlighted are ‘The wall of silence’, ‘Blame and distrust’ and ‘Breaking the silence’. These relate to men and partners’ accounts of their interactions and relationships with HCPs and reliance on their expertise and guidance towards diagnosis and treatment of prostate disease.

The final chapter of this thesis, chapter 7, is integrated with the substantive theory developed and discussions surrounding these. It first presents the core category, ‘Silence among Afro-Caribbean men’ (SAACM) and describes this theory relative to antecedents, relationships, contributors, resolution, adaptation and consequences. It continues to discuss the SAACM theory in relation to current and relevant literature and shows its unique contribution to PCa literature. The chapter then goes on to highlight strengths and weaknesses of the theory before offering a critical appraisal of the research process, limitations of the study and implications for practice, teaching and education and research, and accounts of reflexivity whilst in the field. Lastly, this chapter extensively discusses recommendations for research and practice before concluding the thesis. This completes the introduction to the thesis, and I will now continue to describe TT in context of the study.
1.5 An Overview of Trinidad and Tobago

The last sections of this chapter described the background and focus of the study and outlined the chapters of the thesis. Here, I provide the context to the current study through providing descriptions of TT that are representative of the people and heritage. Firstly, it offers insight into the culture of the people, which illustrates the nation’s rich heritage and diversity. Secondly, it describes the geography and economy of the country, which highlights its unique location with reference to the Caribbean and Americas; and international trade and business relationships respectively. Lastly, it examines the current political situation, which provides the reader with a better understanding of health and social care for this twin isle.

1.5.1 Culture of TT

Here I describe the culture of TT. It starts with a historical overview and then describes the cultural traditions, religion and spirituality.

1.5.1.1 History

TT is a cosmopolitan nation (Sheehan & Lin, 2011), and is considered a model of ethnic diversity (St. Bernard, 2003). These islands were separate territories until 1888 when they joined alliances (Brereton, 1981). Amerindians, comprising of Caribs and Arawaks were the original inhabitants. In the sixteenth century, there was an influx of African slaves from the Atlantic slave trade due to the plantation economy. The island became a British colony in 1802, after repeated invasion and conquest by multiple European powers (Sheehan & Lin, 2011). In 1834, the African slave trade was ended due to emancipation, and East Indians were brought to the island from the Sub-Asian continent in the nineteenth century to replace these workers. These indentured labourers mainly worked on the sugar cane plantations. Most of the Africans settled in Tobago, and Trinidad experienced an influx of French and British settlers and emigrants from neighbouring Caribbean islands, such as Martinique, Guadeloupe, Dominica and Grenada. Presently the population reflects African, Chinese, East Indian, French, Spanish, Portuguese and Mixed-racial heritage (see Figure. 4). As such the island of Trinidad is multiracial, multicultural and multilingual although the main language is English; whereas Tobago is mainly comprised of African settlers (Robinson et al., 2018; Sheehan & Lin, 2011).
1.5.1.2 Religion and spirituality

There are many religious groups in TT due to the diverse nature and history of the population. These are Christianity, Islam, Hinduism, Protestants and smaller non-Christian groups (Munasinghe, 2001) (see Figure 5). Both cultural and religious beliefs inform people’s identity in this nation. Each religion is characterized according to its doctrine and teaching, as well as family life, roles within the family, marriage and upbringing of children (St. Bernard, 2003).
1.5.1.3 Family life

The cultural diversity that exists in TT informs family customs. Each cultural group possesses distinct beliefs, values and traditional practices. Children are expected to honor, demonstrate good behaviour and be obedient across most cultural groups in TT. Within the East Indians’ cultural group, love and care are reciprocal. It is expected that parents care for their children and when parents are elderly, the same be done in return. Males are regarded superior to females among Indo-Trinidadians. Display of public affection is not allowed among the Chinese in TT (Sheehan & Lin, 2011).

There are various family structures in TT. These are nuclear, single parent, extended, and common-law families. Nuclear and extended families mainly exist among East Indians and Chinese in TT. The role of the father towards disciplining children, as economic provider and protector; and mother as care provider has evolved over the last three decades (Roopnarine et al., 2013). Currently, women are mainly breadwinners throughout TT. Visiting union, in which mothers live in their parents’ home are quite common in TT. Absent fathers are prevalent within the African cultural group in Trinidad, unlike the African settlers in Tobago that are mainly patriarchal. These result in matriarchal or single-mothers and child shifting in Trinidad, in which children are sent to live with relatives (Roopnarine et al., 2013; Sheehan & Lin, 2011).

1.5.2 Organization of healthcare in TT

TT functions under a two-tier healthcare system. The Ministry of Health (MOH) oversees the healthcare system and sets policies, goals and targets for the Regional Health Authorities (RHA) in TT (The Ministry of Health, 2018). The MOH depends on a network of health centres and district health facilities. These are managed by the RHAs, the private sector and Non-Governmental Organisations to provide public health care services (The MOH, 2018).
Currently, there is no public health insurance system in TT. Although some services at the Eric Williams Medical Science Complex (EWMSC) require payment if individuals are referred outside the public health care system, the Government generally finances public health care. As such the five autonomous RHAs offer free services and direct provision of healthcare to residents of this population in accordance to geographic locations. These are The North West Regional Health Authority (NWRHA); North Central Regional Health Authority (NCRHA); South West Regional Health Authority (SWRHA); Eastern Regional Health Authority (ERHA) and Tobago Regional Health Authority (TRHA) (Ministry of Health, 2018) (Figure 6). There are seven major hospitals throughout TT that serves 1.4 million people (TT Demographic Report, 2012). These are the Port of Spain General Hospital (POSGH), EWMSC, San Fernando General (SFGH) and Teaching Hospitals, Sangre Grande Hospital, Point Fortin Hospital in Trinidad and the Scarborough General Hospital in Tobago. Some of the services provided are dentistry, general practice, medicine and surgery, optometry and cancer care. Almost all these hospitals operate on a “walk-in” basis for residents of TT. The leading causes of death for TT are cardiovascular diseases, cancer, diabetes, cerebrovascular disease and physical injuries (Johnson & Rodrigues, 2016; MOH, 2018).
The MOH public health policy (2017) is to establish a National Health Service (NHS) for all patients. It aims to provide a package of services to all residents of TT. This has been approved by Cabinet. Currently, a health needs assessment is in progress. Some health centres have General Practice services implemented, however, the NHS pilot programme is still in its developmental stages (MOH, 2013). One health programme that has been successfully implemented is the Chronic Disease Assistance Plan (CDAP). This provides free pharmaceuticals for chronic diseases. There are various private healthcare facilities throughout TT that provide the same services as public healthcare. Although smaller in numbers than the public sector, the quality of healthcare is considered better. However, the costs at these private healthcare facilities are regarded as expensive. Most people that purchase healthcare privately possess medical insurance (Rambally, 2017). The Central Bank of TT is the regulatory agency of private health insurance in this nation. Private health systems are paid at point of service either out of pocket or through private health insurance (MOH, 2013).

A report from the Pan American Health Organization (PAHO) (2013) showed that TT has one of the region’s highest cancer mortality rates within the Caribbean. Prostate and breast cancer are the two most common cancers among the population of TT (Warner et al., 2016), increasing the economic burden to $2 billion dollars annually. The annual number of cancer deaths increased from 1,201 to 1,417 within the period 2001-2008. For this period, PCa was the most prevalent, reflecting 34% of cancer deaths in the TT population. This was followed by breast (23%), lung (13%) and colorectal (12%) cancers (PAHO, 2013). There were 1390 cancer deaths reflecting 13% of deaths in 2015 (MOH, 2015). The population receives free cervical, breast and colorectal cancer screening, prescription drugs and cancer treatment services at six medical facilities throughout TT (Rambally, 2017). Cancer specialist nurse training commenced in 2008 through collaboration between McMaster University, Canada and UWI, Trinidad (McMaster University, Annual Report, 2009). This consisted of taught modules, research and clinical rotations within oncology centres in Canada, UK and USA. TT is working towards becoming a developed nation by 2020. Another major 2020 vision and direction for TT in the cancer policy is to implement The National Oncology Centre that will incorporate specialists, technology and treatments in the same place (Rambally, 2017). As part of creating a caring society, it also aims to invest more into cancer research, education and training of cancer staff. This aims to improve access and delivery to treatment and provide cancer preventative strategies (Ministry of Health Public health policy (2020), National Strategic Plan).
1.6 Summary

This overview provided the context in which the study is based. The isle of TT was discussed with reference to culture, religion and spirituality, family life, economy and politics and healthcare. Cancer is a high priority in health care management due to the late diagnosis and economic burden in TT. PCa is the highest among men and is a public health concern, as men do not access cancer care services in a timely manner in TT. Cultural and ethnic diversity is important in TT with differences impacting on health and diagnosis.
CHAPTER TWO – LITERATURE REVIEW

This chapter discusses current and relevant literature in relation to men and their partners’ experiences of PCa. It is divided into three parts. In the first part, a systematic literature review that was published in the European Journal of Oncology Nursing (EJON) is presented (King-Okoye et al., 2017). This emphasized the importance of men’s lay beliefs, culture and masculinity towards appraisal and help-seeking for prostate symptoms. In the second part, a review of other relevant literature on men and partners’ experiences of PCa are examined. And a theoretical review of the literature is discussed in accordance to the concepts identified in the literature.

2.1 Part One: Systematic Literature Review

2.1.1 Introduction

PCa is known to be the fifth leading cause of cancer death globally and is the second most common cancer in men (Globocan, 2012). Prostate disease is unique in comparison to other cancers, in that it can be slowly progressive and indolent but also aggressive. This makes it difficult to determine the disease progression through symptoms experienced until it reaches an advanced stage (Esserman et al., 2014). The availability of prostate-specific antigen (PSA) screening programmes and access to health resources are two major factors that determine survival across countries. This is evident among migrants’ experiences of a better prognosis when travelling from a country of low to high provision (Moten et al., 2014). This may not be the only factor for how men interpret and appraise symptoms and seek help may vary across countries and ethnic groups. A recent independent global online and telephone survey showed that 68% of men ignored symptoms of advanced PCa, manifested as bone and body pains, numbness and weakness, which significantly delayed help-seeking (Drudge-Coates et al., 2018). This study was conducted among 867 men with advanced prostate disease and 360 care givers in ten countries from France, Germany, Japan, Italy, Netherlands, Singapore, Spain, Taiwan, UK and USA. Men from higher risk groups for PCa are identified as those with a family history and from Black African or Caribbean origin (Lloyd et al., 2015). These men tend to present to emergency services when symptoms of PCa have reached a stage where they are debilitating and life-threatening (Mayer et al., 2011). Understanding men’s cultural beliefs and perceptions of how they interpret and appraise symptoms and seek medical help is important for understanding factors that impact on risk.
Considerable PCa research has focused on PCa screening among various populations (Lane et al., 2010; Mulhem et al., 2015) and the impact of PCa on the health and wellbeing of men and their families (Lim et al., 2013). However, the research evidence highlights critical gaps on how to help men recognise symptoms earlier. A recent meta-synthesis of qualitative studies was conducted on the relationship between ethnicity and PCa experience (Rivas et al., 2016). They highlighted three specific features in health perceptions: the healthcare provider relationship, spirituality and living on for others. The current review focuses on studies of men’s cultural beliefs and ethnic populations, and asks do these themes impact on help-seeking and is Black and Minority Ethnic (BME) groups different to other groups of men who are diagnosed with PCa? This narrative review examines both qualitative and quantitative studies asking the question: how men’s beliefs relating to bodily changes including symptom appraisal of PCa affect their interpretation and help-seeking actions, especially from culturally diverse groups.

2.1.1.1 Definitions, scope and study aims

Beliefs are socially constructed by individuals in relation to the environment and culture, which are adapted depending on situations and relationships (Radley and Billig, 1996). A disturbance in the body triggers beliefs that are embedded within cultural expectations that enable individuals to interpret these changes as normal or requiring medical attention (Bury, 1982; Radley, 1994). As such, the aim of this review is to explore men’s beliefs in relation to symptom appraisal for bodily changes suggestive of PCa and how these affect their help-seeking behaviours and actions. Comparison of cultural and ethnicity differences in help-seeking behaviours are explored across these studies. The pre-diagnosis phase considers symptom appraisal and help-seeking. In this review, symptom appraisal is defined as the detection of bodily change(s), attribution to an organ or disease/illness and interpretation/perceptions as needing medical help (Scott et al., 2013). Help-seeking is defined as a decision to seek medical help, schedule an appointment and discuss health concerns/bodily changes with a Health Care Provider (HCP) (Scott et al., 2013).
2.1.2 Methods

The following databases were searched for eligible studies: CINAHL full text, Psych Articles, Psych INFO, MEDLINE, Psychology and Behavioural Sciences and PROQUEST.

2.1.2.1 Inclusion criteria

Peer reviewed studies that were of empirical researches were included in the narrative review (2004-2017) because screening measures and treatment has substantially changed coupled with the significant rise in PCa incidence rates between this period (Weiner et al., 2016). Men from all ethnic groups and nationalities with self-reported beliefs that identified at least one symptom or bodily change relevant to prostatitis, benign prostatic hyperplasia, and PCa of differing stages, including lower urinary tract symptoms were included. Studies that focused on men diagnosed with PCa but did not specify bodily change(s) experienced were still included but placed under general symptoms once beliefs, interpretation and help-seeking actions were identified. These studies with available abstracts and in the English Language were accepted as part of the review. See Appendix 1 for an outline of the inclusion criteria for the systematic review.

2.1.2.2 Exclusion criteria

Studies that explored partners, carers and health care professionals' beliefs were excluded from the review. Studies that were not published in the English Language were not considered for inclusion in this review. And studies that did not have abstracts or conducted prior to the year 2004 were excluded.

2.1.2.3 Search strategy

Searches were completed using appropriate MESH terms, keywords and subject headings on each abstract. Boolean operators were utilised to capture studies as per eligibility criteria. References cited in papers that met the inclusion criteria were explored for potential inclusion in the review. All papers from searches were uploaded into RefWorks and EPPI reviewer 4 software. Papers were screened for duplicates and for eligibility. Initially, papers were scanned by looking at the title and
abstracts; and subsequently by reading the full text of the article. All three authors studied, and discussed articles included for the review. Studies were critiqued using the respective critical appraisal tools and evaluative tool for mixed methods studies as highlighted in supplementary materials and presented using The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) tool as seen in Figure 7. Data were extracted from individual papers and tabulated in accordance with the research question.
Figure 7. PRISMA flow diagram
2.1.3 Results

A total of 18 articles that met the criteria for the review were included and are outlined in Appendix 2. These consisted of 9 qualitative studies (Anderson et al., 2013; Blocker et al., 2006; Hale et al., 2007; Matthew et al., 2011; Nanton & Dale, 2011; Ng et al., 2013; O’Brien et al., 2005; Shaw et al., 2008; Taghipour et al., 2010), 5 quantitative studies (Apostolidis et al., 2009; Gulpinar et al., 2011; Metcalfe et al., 2008; Shabsigh et al., 2004; Whitaker et al., 2014) and 4 studies that utilised mixed-methods (Emery et al., 2013; Ertel et al., 2016; Place et al., 2011; Sarma et al., 2008). The methodological framework utilised for qualitative studies consisted of interpretive phenomenology, thematic analysis and grounded theory; in which face-to-face and telephone interviews and focus groups were conducted. The quantitative studies utilised large-scale surveys, population-based cohorts, epidemiological interviews and self-administered questionnaires.

The critical appraisal and evaluative tools for mixed methods scoring systems highlighted studies in the review as good or fair. Sample sizes ranged from 7-55 men for qualitative studies; 239-1958 for quantitative studies and mixed studies ranged from 14-165 men. Of the 18 studies included in the review, 8 were conducted in the UK (Anderson et al., 2013; Metcalfe et al., 2008; Whitaker et al., 2014; O’Brien et al., 2005; Nanton and Dale, 2011; Shaw et al., 2008; Place et al., 2011; Hale et al., 2007), 2 were conducted in the USA (Blocker et al., 2006; Sarma et al., 2008) 1 in the Caribbean (Ng et al., 2013), 1 study in Australia (Emery et al., 2013), 1 in Turkey (Gulpinar et al., 2011), 1 in Iran (Taghipour et al., 2010), 1 in Greece (Apostolidis et al., 2009), 1 in Canada (Matthew et al., 2011) and 2 were conducted in multiple countries (Shabsigh et al., 2004; Ertel et al., 2016).

The men were representative of African, Afro-Caribbean, White Caucasian, and Asian ethnicity. Some studies did not identify the ethnicity of the research participants. The ages of men ranged from 20-91 years comprising of men who were diagnosed with PCa, benign prostatic hyperplasia (BPH), enlarged prostate and lower urinary tract disorders. Some men were not diagnosed with any prostatic diseases (Blocker et al., 2006; Matthew et al., 2011; Whitaker et al., 2014; Sarma et al., 2008). However, self-reported symptoms relevant to these diseases or conditions were evident. Four studies included women (Blocker et al., 2006; Ng et al., 2013; Whitaker et al., 2014; Shaw et al., 2008). Nevertheless, only men’s accounts were considered for the review. The populations were representative of diverse ethnic groupings.
However, beliefs identified were not contextualised from a cultural perspective. This review will explore beliefs about bodily changes as it pertains to ethnic groups from the studies.

2.1.3.1 Men’s Beliefs and the Symptom Experience

Men’s beliefs identified in the studies related to early symptom experiences are discussed under the following headings: (i) beliefs associated with danger and alarm signs, such as haematuria and painful urination, (ii) beliefs associated with physical and urinary symptoms, which were a normal sign of ageing or transient and (iii) beliefs linked to psychosocial factors, which were related also to masculinity. Lastly, (iv) the link between beliefs and emotional reactions to bodily changes identified in these studies are discussed in relation to help-seeking.

2.1.3.2 Beliefs associated with danger and alarm signs

The sight of blood in urine or semen and severe pain due to cystitis and prostatitis accelerated symptom appraisal among men of all ethnicities across studies. This was due to the belief that symptoms were indicative of danger and fatal signs that were connected to a cancerous growth and ill health (Anderson et al., 2013; Emery et al., 2013; Ertel et al., 2016; Place et al., 2011; Hale et al., 2007). Conversely, men that did not detect these symptoms experienced severe delays in symptom appraisal because they held the belief that the absence of blood and severe pain did not warrant any cause for concern (Emery et al., 2013; Hale et al., 2007).

2.1.3.3 Beliefs associated with physical and urinary symptoms, which were a normal sign of ageing and transient

Urinary symptoms, such as urinary dribbling, burning, weak urine stream and urinary hesitancy were experienced by men pre-diagnosis of PCa and construed as non-cancerous and trivial. Men described urinary symptoms as irritating and bothersome but not serious because of the belief that these were related to normality, ‘an old man’s disease’ (Hale et al. 2007, p. 9) and the ageing process (Hale et al., 2007; Emery et al., 2013; Taghipour et al., 2010; Place et al., 2011). Healthy men from differing countries also shared this belief that such symptoms were a normal part of ageing (Shaw et al., 2008; Whitaker et al., 2014; Apostolidis et al., 2009;
Sarma et al., 2008). Men also experienced significant delays in symptom appraisal because they perceived that urinary changes would subside with time and continued to work and perform activities of daily living (AODL) without interference, which reflected stoicism (Emery et al., 2013; Sarma et al., 2008). Cultural differences in men’s beliefs towards urinary symptoms highlighted the role of infection (Metcalf et al., 2008; Whitaker et al., 2014; Ertel et al., 2016) and stressful situations (Blocker et al., 2006). These were believed to be responsible for changes in men’s urine flow (Anderson et al., 2013) especially where they had a history of urinary tract infection (Place et al., 2011).

2.1.3.4 Beliefs linked to psychosocial factors and masculinity

Men held beliefs that were influenced by their self-image and self-esteem particularly towards symptoms of urinary leakage (Metcalf et al., 2008; Emery et al., 2013; Hale et al., 2007; Place et al., 2011) and erectile dysfunction (Hale et al., 2007; Shabsigh et al., 2004; Gulpinar et al., 2011) that were embarrassing or had stigma associated. Men described their experiences of urinary leakage and frequency in urination as a shameful one. They likened these changes to babyhood, which significantly affected their self-image (Hale et al., 2007). Some men demonstrated a denial of symptoms because they believed that symptoms could mean something much worse such as terminal illness (Hale et al., 2007; Taghipour et al., 2010).

Cultural differences were clearly seen in these men’s perceptions of masculinity. Iranian men stated that sex was part of their social identity, which they believed doctors could not relate to (Taghipour et al., 2010). Sexual changes reported to be experienced by men diagnosed with PCa were impotence, decreased libido, erectile and ejaculation dysfunction (Anderson et al., 2013; Hale et al., 2007; Place et al., 2011). Changes associated with erectile dysfunction were perceived as taboo, especially for African and Afro Caribbean men to talk about their sex life. Their sexual organs were believed to be private and precious which delayed symptom appraisal (Anderson et al., 2013).
2.1.3.5 The link between beliefs and emotional reactions to bodily changes in relation to help-seeking

Men’s beliefs towards help-seeking for prostate symptoms were influenced by their social network, such as family, friends, the media; spirituality; accessibility to healthcare providers via appointment scheduling; and the belief in the use of herbs as discussed below:

2.1.3.5.1 The influence of friends, family, the media and spirituality

Social contacts within the community, friends and families also influenced help-seeking behaviours for men across all studies (Hale et al., 2007, Ertel et al., 2016; Place et al., 2011; Taghipour et al., 2010). Some British men consulted with other men diagnosed with prostate problems to compare symptoms thus sanctioning the need to see a doctor concerning their urinary symptoms. Hearing reports of failed surgery from peers instilled fear and impeded help-seeking (Hale et al., 2007). Australian and British men searched the Internet, medical books, social groups, the church and the media for information before consulting a doctor, which delayed help-seeking with medical staff (Ertel et al., 2016; Place et al., 2011). Men identified the role wives played towards help-seeking, which were noted across all cultures. Iranian and Afro Caribbean (Taghipour et al., 2010; Nanton & Dale, 2011; Ng et al., 2013) men were also influenced by social contacts to use herbs for urinary changes due to traditional family cultural practices. Wives of British and Iranian men were instrumental towards help-seeking for blood in urine and semen through observing their spouses/partners frequent visits to the bathroom and discomfort from painful urination (Place et al., 2011; Taghipour et al., 2010); urinary changes (Hale et al., 2007) and significant weight loss (Place et al., 2011). Spouses of African and Caribbean men attended consultations and were involved in treatment-related decisions (Ng et al., 2013). African men’s beliefs were influenced by spirituality. Those with a strong faith were motivated to attend health promotion practices because of their strong convictions developed from church attendance (Blocker et al., 2006; Nanton & Dale, 2011).

2.1.3.5.2 Appointment scheduling, GP access and private healthcare

Some men believed they could not get a timely appointment because they were too busy with work. This study highlighted that British men did not encounter problems scheduling appointments (Place, 2011). Conversely, some British men turned to private healthcare with
the belief that this was superior to local healthcare (Hale et al., 2007). Use of private healthcare was also reported among Afro Caribbean men who had scheduling delays for symptoms experienced (Ng et al., 2013). Australian men were concerned about the continuity of care with a regular GP and delayed booking an appointment if the GP was not available. Men that lived very far from their GP postponed help-seeking because of this (Emery et al., 2013). Some British men believed in seeking help from a specialist doctor because of their faith in these doctors (Ertel et al., 2016). Gaining access to specialist doctors contributed significantly to delays in help-seeking (Ertel et al. 2016).

There were significant cultural differences in help-seeking behaviours. Iranian and Afro Caribbean men that had prior experiences with medical care, they were distrustful of the medical system, which contributed to significant delays (Blocker et al., 2006; Ng et al., 2013; O’Brien et al., 2005; Taghipour et al., 2010). Men who developed sexual changes, such as impotence they believed that doctors were uncaring and unwilling to speak to them (Taghipour et al., 2010). Some Turkish men delayed discussing sexual concerns if their GPs were of the opposite sex (Gulpinar et al., 2011). Conversely, British men held the belief that their consultation would be better if seen by female GPs whom they perceived to be more caring and sensitive to their concerns (Hale et al., 2007). Similarly, some African and Afro Caribbean men diagnosed with PCa recalled their GP giving them information that men at an older age were not expected to be sexually active when presenting with sexual changes. This deterred men from speaking freely about their sexual changes (Nanton and Dale, 2011). Some British and Afro Caribbean men also believed that prostate problems were inferior compared to those with HIV/AIDS and co morbidities, such as diabetes, cardiac problems and high cholesterol, which delayed symptom reporting to their doctors (Hale et al., 2007; Anderson et al., 2013; Ng et al., 2013).

2.2.1 Discussion and implications

The review highlighted several studies that examined the relationship between cultural beliefs and help-seeking behaviours. But few explored the complexities in identifying men’s beliefs for men who were asymptomatic as well as those diagnosed with PCa. There is an urgent need for empirical research to examine men’s beliefs from a cultural context as to how these may impact on care pathways for PCa, especially among men of African and Caribbean origin considering they are at a higher risk of developing prostate disease (Lloyd et al., 2015). The review highlighted significant cultural differences regarding perceptions of trust in the
medical community and notions of masculinity during the symptom experience, which subsequently affected beliefs towards help-seeking behaviours for urinary and sexual changes suggestive of prostate symptoms. This was viewed through the man’s eyes as feelings of suspicion, conspiracy and mistrust, in which men preferred to manage symptoms using herbs rather than with Western medicine (Mulugeta, 2014). Delays in scheduling appointments also underscored the cultural disparities in help-seeking behaviours.

Beliefs connected to an extrinsic locus of control have been postulated to significantly influence help-seeking actions as individuals believe the control over their health is solely dependent on health care provider’s actions (Baumeister et al., 1994). As such perceptions of an uncaring health system can deter help-seeking thus contributing to significant delays to care pathways for PCa (Moffat, 2010). The review also showed that Black men were less likely to seek health information through researching the Internet and reading different forms of media, which have implications for informing appraisal of symptoms. Psychologists’ purport that those that are intrinsically motivated are more likely to seek help for health concerns (Baumeister & Bushman, 2013). However, beliefs may alter depending on prior experience and social accounts of trust and interpersonal relationships with providers and the health system, which can significantly affect the agent self towards seeking medical help (Moscovici, 1993). African American men who were newly diagnosed with PCa were hindered from help-seeking because of prior experiences of medical care. Their distrust was related to a lack of communication with their doctors in consultations (Yang et al., 2013).

The importance of partners/women and the lay referral network were highlighted in this review as being significant to interpretation and help-seeking decisions. Radley (1994) posits that lay referral network can help men from similar social class make sense of bodily changes and seek help, as a trusting relationship is vital for symptom interpretation through ‘sharing concerns’ and making decisions towards help-seeking. This highlights the significance of cultural capital and the influence of cultural settings (Zola, 1966) for BME men. This support studies in which men from similar socioeconomic background and level of education were more inclined to seek help for prostate bodily changes after discussing symptoms with family members, friends and colleagues in their workplace, church and communities (Williams et al., 2008; Shokar et al, 2010). The agent self is activated through education, which can occur informally through the lay referral network or from prior and personal experiences (Radley, 1994). Studies have identified the importance of self-efficacy, or the belief that one can
accomplish a specific task (Bandura, 1977); in this case recognising and interpreting symptoms correctly can only be done through knowledge, which helps with the interpretation of symptoms. Knowledge gained can influence beliefs about symptom experience and in turn help-seeking behaviours (Griffith et al., 2011; Drake et al., 2010).

Fear has been looked at as both a deterrent and facilitator to help-seeking in relation to embarrassment and denial of symptoms and fear of a PCa diagnosis respectively (Drake et al., 2010). Miceli & Castelfranchi (2015) postulate that fear is a compelling stimulus to cognitive processing that is linked to realism, the belief towards acceptance of reality’ (Miller, 2009). This was a stimulus for help-seeking in the current review about erectile dysfunction and urinary symptoms. Individuals were found to rely on individual beliefs as a response to fear (Macleod et al., 2009) or reach out for help through seeking medical advice (Dubayova et al., 2010). The significance of the lay referral network has implications towards symptom interpretation and help-seeking. Hope was linked to optimism, defined as ‘a belief that good will prevail’ (Chang, 2009) which contributed to delays in help-seeking. This was reflected through stoic men (Emery et al., 2013) and self-management strategies (Apostolidis et al., 2009; Nanton & Dale, 2011). It has been found that positive beliefs of optimism facilitated help-seeking among men with prostate symptoms (Macleod et al., 2009). Dread was linked to pessimism, defined as ‘a belief that the worst will happen’ (Chang, 2009). Men from these studies equated a cancer diagnosis to hopelessness and death (Blocker et al., 2006; Hale et al., 2007). Having the knowledge that PCa if detected early can be effectively treated could inform men’s beliefs.

Identifying underlying assumptions behind men’s cultural beliefs can be used to develop public health strategies towards early interpretation, help-seeking and screening associated with prostate symptoms to improve accessibility to health services and to diagnosis. For example, the church can be used as a forum for health promotion activities to engage men in discussion such as when to seek help with bodily changes associated with the prostate gland. This can be done through religious leaders since spirituality was highlighted in this review as significant to men’s cultural beliefs. Bodily changes associated with prostate disease and PCa affected men’s interpretations and help-seeking behaviours among both healthy men and men diagnosed with prostate disease, as well as among knowledgeable (Blocker et al., 2006) and knowledge deficient populations (Shabsigh et al., 2004; O’ Brien, Hunt & Hart, 2005, Apostolidis et al., 2009; Place et al., 2011; Hale et al., 2007; Taghipour et al., 2010). This review
underscores a need for further empirical research into cultural beliefs about bodily changes relevant to prostate health and how it affects interpretation and help-seeking actions with implications for health inequalities that can exist among certain groups of men and in particular BME men, since these men are at higher risk of developing prostate disease and often delay help-seeking for symptoms suggestive of PCa, as seen in the review (Anderson et al., 2013; Blocker et al., 2006; Nanton and Dale, 2011; Ng et al., 2013; O’Brien et al., 2005). Many studies showed men’s reliance on their wives’ involvement in recognising and seeking help for the symptoms experienced and help men to interpret and seek help (Blanchard et al., 2005; Eastland and Dancy, 2013; Friedman et al., 2009; Friedman et al., 2012). An understanding of men and their partners’ beliefs could highlight facilitators and barriers to symptom appraisal, symptom interpretation and help-seeking.

2.2 Part Two: Review of Literature on men and partners’ experiences of PCa

Introduction

The previous part highlighted a systematic review of peer-reviewed studies and recently published articles that specifically focussed on men’s beliefs about bodily changes relevant to PCa and factors that influence help-seeking actions for these symptoms. The findings show how men’s beliefs about the warning signs of PCa, such as blood in the urine and painful symptoms; and their interpretations of bodily changes as being associated to ageing, normality and infection significantly delayed appraisal of symptoms and help-seeking actions. These were consistent among men of differing ethnicities across all studies. Moreover, the review highlights a dearth of studies with this research focus and underscores a need for further empirical research.

In this part of the literature chapter, I explore a range of empirical and theoretical literature about men and their partners’ experiences of PCa through diagnosis and treatment. I first outline the aim of the review and highlight key terms used to search electronic databases and grey literature. I then provide the search strategy and the eligibility criteria utilized for the literature review as illustrated in Table 1. The search process and results of these are discussed to maintain transparency and reproducibility. In so doing I then describe the data extraction and quality assessment of studies selected for the review using the SMSR assessment tool.
(Pluye et al., 2009). I discuss the synthesis of studies in relation to the following headings: men’s experiences of PCa, the impact of the illness experience, help-seeking experiences, couples experiences of PCa, and partners’ experiences of PCa. And finally, I discuss the results of the narrative synthesis employed utilizing guidance from the Centre for Reviews and Dissemination (2008) and Popay et al. (2006) in relation to knowledge deficiencies, lack of awareness and uncertainty; poor communication, distrust and lack of support, and role(s) of women.

2.2.2 Aim of the literature review

The primary aim of this literature review was to extract empirical evidence that would highlight men and partners’ experiences of PCa through diagnosis and treatment. For this review, experiences of PCa are defined as reports, accounts, views, perceptions and beliefs of the disease process; appraisal of symptoms, help-seeking actions and behaviours, and diagnosis and treatment of the condition. This also includes how care was organized and delivered to meet their needs (Sinfield, 2008).

Awareness, knowledge, communication with HCPs, health systems and other key terms were also considered. The scope of the review included men and women from all ethnicities and nationalities to capture meanings and comparisons across ethnic groups and countries.

2.2.3 Search strategy

Seven databases inclusive of medical, psychology and sociology records were screened for relevant literature: CINAHL, PsycINFO, Psychology and Behavioural Sciences, PsycARTICLES, MEDLINE, PsycBOOKS, and PROQUEST. These were inclusive of academic journals, books, position statements, and reviews. Key terms such as prostate, PCa, prostate disease, prostate neoplasms, bodily changes, prostate symptoms, health behaviour, help seeking, culture, PCa screening, experiences, understanding, associated risks, views, attitudes, perceptions, beliefs, knowledge, awareness, spouse, appraisal, diagnosis and treatment were utilized to capture relevant sources. Hand searches were also conducted, and the references cited in relevant papers were also screened for potential inclusion. Cancer sites, such as PCa UK, Cancer Research UK, NICE were also searched for healthcare policies, statistics, studies conducted
and guidance. Searches were limited to literature in English-language from 2000-2017 because of the changes in prostate screening measures. The PES framework was used to capture all categories of the main research question. Hence, P=population (men and partners), E=exposure (experiences), S=subject (PCa). Studies that explored or investigated men and their partners in relation to key terms highlighted were included if they were among the research sample.

Studies that targeted survivors of PCa and their spouses; those that focused on clinical effectiveness of care, such as clinical interventions, quality of life and developing tools; and studies that explored carers’ experiences of PCa were excluded. Systematic reviews were excluded to avoid duplication of findings. However, references within reviews were searched for eligible studies. And studies that focussed on other aspects other than patient experiences were excluded.

2.2.4 Eligibility criteria for the literature review

Based on the research paradigm, ‘experiences of PCa’, the following inclusion and exclusion criteria were utilized to select relevant materials. This is shown in Table 1.
Table 1 shows eligibility criteria for literature review

<table>
<thead>
<tr>
<th>Inclusion criteria</th>
<th>Exclusion criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>English Language literature</td>
<td>Non-English Language literature</td>
</tr>
<tr>
<td>Abstract available</td>
<td>No abstract available</td>
</tr>
<tr>
<td>Men diagnosed with PCa</td>
<td>Studies focused on men’s health issues other than for prostate problems</td>
</tr>
<tr>
<td>Female partners of men diagnosed with PCa</td>
<td>Male partners, PCa survivors</td>
</tr>
<tr>
<td>Men’s experiences of appraisal, help-seeking, diagnosis, and treatment for PCa</td>
<td>Quality of life, intervention studies, end-of-life and palliative care for PCa; developing tools or assessment of tools</td>
</tr>
<tr>
<td>Men and partners’ accounts</td>
<td>Accounts of health care providers</td>
</tr>
<tr>
<td>Studies conducted from 2000-2017</td>
<td>Studies conducted prior to 2000</td>
</tr>
</tbody>
</table>

2.2.5 Data extraction and quality assessment

The Critical Appraisal Skills Programme (CASP) assessment tools and an evaluative tool for mixed methods were used for the systematic review that focused mainly on men’s belief and factors that impinge on their appraisal of bodily changes and help seeking actions (King-Okoye et al. 2017). It was necessary to utilize another tool to assess the quality of a wider number and range of studies that would also allow for data extraction. As such the system for mixed methods research and mixed studies reviews (SMSR) assessment tool by Pluye et al. (2009) was selected. A more current version of this tool is available (Pluye et al. 2011). However, as this is still in development, the former version of the tool was deemed more appropriate for this review. Additionally, the use of the SMSR assessment tool has demonstrated reliability and validity (Pluye, 2009), as evidenced in its application in 17 mixed systematic reviews in health sciences with a Kappa score of more than 0.8 (Pace et al., 2012; Souto et al., 2014).

2.2.6 SMSR assessment tool criteria

There are fifteen criteria that are used to appraise studies in four methodological categories in the SMSR assessment tool (Pluye et al., 2009) as outlined in Table 2.
Table 2 shows the SMSR too developed by Pluye et al., 2009

<table>
<thead>
<tr>
<th>Types of study</th>
<th>Methodological quality criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>Qualitative</td>
<td>Qualitative objective or question</td>
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<tr>
<td></td>
<td>Appropriate qualitative approach or design or method</td>
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<tr>
<td></td>
<td>Description of the context</td>
</tr>
<tr>
<td></td>
<td>Description of participants and justification of sampling</td>
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<tr>
<td></td>
<td>Description of qualitative data collection and analysis</td>
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<td></td>
<td>Discussion of researchers’ reflexivity</td>
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<tr>
<td>Quantitative experimental</td>
<td>Appropriate sequence generation and/or randomization</td>
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<td></td>
<td>Allocation concealment and/or blinding</td>
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<tr>
<td></td>
<td>Complete outcome data and/or low withdrawal/drop-out</td>
</tr>
<tr>
<td>Quantitative observational</td>
<td>Appropriate sampling and sample</td>
</tr>
<tr>
<td></td>
<td>Justification of measurements (validity and standards)</td>
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<tr>
<td></td>
<td>Control of confounding variables</td>
</tr>
<tr>
<td>Mixed methods</td>
<td>Justification of the mixed methods design</td>
</tr>
<tr>
<td></td>
<td>Combination of qualitative and quantitative data collection-analysis techniques or procedures</td>
</tr>
<tr>
<td></td>
<td>Integration of qualitative and quantitative data or results</td>
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</tbody>
</table>

2.2.7 Synthesis of included literature

A narrative synthesis approach was utilized to discuss the characteristics and findings of the included literature for this review, as outlined by Centre for Reviews and Dissemination (2008) and Popay et al. (2006) guidance resources. This approach was considered best for the review based on the diversity of studies in relation to the settings, variety of methodological approaches and outcome measures (Thomas & Harden, 2007). The Centre for Reviews and Dissemination guidance (2008) presents the narrative synthesis approach to a systematic review as four elements as outlined in Table 3. Three of these elements were utilized for the synthesis of included studies, as the first element, which is developing a theory was not applicable to the grounded theory framework for this study.
Table 3 shows the stages in the narrative synthesis (Centre for Reviews and Dissemination, 2008 p. 49)

2.2.8 Assessing the robustness of the synthesis

This pertains to the quality and strength of the synthesis process in accordance to four criteria: the stability of the methodology utilised, the suitability of the study design in answering the review question, an assessment of the overall weightings of the evidence, and the study relevance (Popay et al., 2006). To avoid risk of bias, a critical discussion was employed. Reflecting critically on the synthesis process, focussed on all aspects of the methodology utilized. This is critical to identifying possible limitations and potential sources of bias in the approach taken for the synthesis (Centre for Reviews and Dissemination, 2008).
2.2.9 Developing a preliminary synthesis of findings of included study

The first step is the selection of tools to organize the preliminary synthesis of findings (Centre for Reviews and Dissemination, 2008). The findings of studies consisted of diverse research designs, such as qualitative, quantitative and mixed methods. As such, quantitative findings were first transformed into a common measure. For example, the groupings and clusters tool were utilized at this stage. This involved the organization of studies into groups that had similar patterns or results in relation to the review question. For example, studies that identified men’s knowledge of PCa were grouped together. The findings that influenced, contributed to or hindered knowledge were coded in relation to this. These were then grouped together.

2.2.10 Exploring relationships within and between studies

Conceptual mapping was utilized to identify basic concepts underpinning studies both empirically and conceptually (Centre for Reviews and Dissemination, 2008). This helped to illustrate and group commonalities, arguments, relationships between and across studies and gaps in the literature. The influence of heterogeneity was explored across studies, that is, the context of the potential sources of variations. All aspects of the research process were examined such as sample, setting, interview questions, and types of research questions, data collection methods and choice of methodology that would account for these variations.

2.2.11 Characteristics of included studies

Studies utilized postal surveys (n=1), cross-sectional surveys (n=2), questionnaires (n=3) and telephone/faceto-face (n=2), semi-structured (n=16), in-depth (n=8) and focus group interviews (n=7); and computer-assisted telephone interviews (n=1). A range of methodologies were utilized, such as grounded theory (n=5), phenomenology (n=9), mixed methods (n=1), critical realism (n=1), thematic analysis (n=11), ethnography (n=1), descriptive statistics (n=2), mean and standard deviation (n=1), logistic regression (n=1), chi-square analysis (n=1), and content analysis (n=2). Sampling sizes ranged from 9 – 60 participants. Ages ranged from 39-95 years, and were representative of African and Afro Caribbean, Latino, White, Asian and East/South Indian ethnicity. Countries represented were UK, USA, Canada, Namibia, Australia, Norway, and Sweden.
2.2.12 Aims of included studies

Eight studies highlighted men’s experiences of PCa from a general perspective (Anderson et al., 2013; Cayless et al., 2010; Chapple & Ziebland, 2002; Krumwiede & Krumwiede, 2012; Nanton & Dale, 2011; Salomo et al., 2016; Wenger et al., 2013). This was inclusive of one study that examined men’s experiences of cancer, however one participant diagnosed with PCa was among the research participants (Stapleton & Pattison, 2015). Three studies examined PCa in relation to men’s illness experience and the impact of the disease (Baker et al., 2016; Fitch et al., 1999; Kelly, 2009). Four studies investigated men’s diagnosis experiences (Halbert et al., 2010; Lehto et al., 2015; Korfage et al., 2006; Mathers et al., 2011). Three studies explored men’s experiences of the post-diagnosis phase (Bradley et al., 2006; Jonsson et al., 2010; Wall et al., 2013).

A total of nine studies that were included in this review explored various aspects of treatment. These were inclusive of men’s experiences of active surveillance (Berger et al., 2014), radiotherapy (Kelsey et al., 2004; Sattar et al., 2018; Smith et al., 2017), hormone therapy (Ervik & Asplund, 2012; Ng et al., 2006), pre-surgery and chemotherapy (Sattar et al., 2018) and prostatectomy (Milne et al., 2008; Walsh & Hegarty, 2010; Wennick et al, 2017). Six studies explored couples’ experiences of PCa in relation to diagnosis and treatment (Gray et al., 2000a), decision-making (Boehmer & Clarke, 2001a; O’Callaghan et al., 2014); aspects of care (Sinfield et al., 2008); couples’ experiences (Harden et al., 2002) and the impact of knowledge and awareness along care pathways (Docherty et al., 2007). Three studies examined partners’ experiences of PCa in relation to daily living (Ervik et al., 2013), their understanding of spousal experiences of the disease and subsequent treatment (Carlson et al., 2001; Wootten et al., 2014).

2.2.13 Studies that broadly examined men’s experiences of PCa

Of the 36 studies included in the review, 8 studies broadly examined men’s experiences of PCa. All these studies were mainly conducted in the UK and utilized a qualitative framework. The research participants were predominantly White ethnicity. Methodologies employed were phenomenology, grounded theory and thematic analysis. Samples ranged from 1-52
men, within the ages of 39-95 years. Even though emerging themes highlighted core concepts like masculinity, for example, the focus of these studies was related mainly to physical aspects of prostate disease with an oversight of psychological aspects such as men’s beliefs and perceptions of the experiences.

For instance, Anderson et al (2013) explored seven African and Afro Caribbean (60-76 years) men’s experiences of PCa via in depth face-to-face interviews, utilizing Braun & Clarke’s thematic conceptual framework. The men in this study received various treatment, such as active surveillance (n=1), hormonal therapy and radiotherapy (n=4) and post prostatectomy procedures (n=2).

The men’s experiences were symbolized as four themes. Disease prompted awareness reflected men’s knowledge gained about PCa through social contacts. Appraising perceived myths of PCa through beliefs demonstrated how men’s beliefs influenced their experiences amid a lack of health education about prostate health. This contributed to fear and increasing anxiety about diagnosis and treatment effects. Checking up as a necessary evil described men’s knowledge of the importance of getting the DRE despite their beliefs and perceptions of pain, discomfort and invasion of privacy. Defining and constructing factors that influenced screening uptake referred to men’s beliefs towards screening. Ageing and the role of GPs towards motivating men were key facilitators of PCa screening. Family and friends were both facilitators and barriers to care. Knowledge deficits and a lack of health education and promotion and poor awareness regarding PCa underlined all elicited themes. The authors of this study did identify limitations such as small sample size and a lack of representativeness. Even though the authors did not highlight the impact of beliefs as a major theme arising from findings, this is evident among three of the themes.

Supporting excerpts do not adequately reflect men’s beliefs and taboos even though these were highlighted in the interview guide. Additionally, issues of masculinity are elicited from the data excerpts. For example, one participant stated that ‘Women have always been much more ready to discuss even personal issues than men do’ (p. 1302). This can be interpreted as one attribute of masculinity, that is, non-exposure of vulnerability (Connell, 1995; 2016). Nevertheless, the findings did highlight men’s low awareness and knowledge of PCa.
Men’s experiences of PCa were examined through the lens of masculinity in three of these studies that had a broad focus. Chapple & Ziebland (2002) conducted unstructured interviews with 52 men between the ages of 52-80 that were predominantly White British. The aim was to explore how the disease process and treatment impact perceptions of self, their bodies and roles inclusive of masculinity. Most of these men were receiving hormonal and radiation therapy. The findings reported men’s help-seeking behaviours and experiences of treatment. Some connections to masculinity were elicited such as the macho image of men, concealment of emotions described, as ‘men don’t cry’ and weakness, and worry over the impact of the illness on their role as breadwinner of the family. This was also inclusive of sexual and physical burdens. Although some actions linked to masculinity were evident in the study, these were not considered as part of the analysis. For example, all but one of the men preferred to be interviewed by a female rather than a male researcher. However, the findings were instrumental towards demonstrating men’s embodiment of masculinity in relation to PCa.

Wenger (2013) developed a substantive theory of the assaults of cancer utilizing a gender lens framework to examine how men make sense of cancer. Canadian men diagnosed with a range of cancers were interviewed (n=30). Only men’s accounts of PCa experiences were included in this review. Utilizing grounded theory, four themes emerged. These were a troubled future, which described the diagnosis of cancer and fears regarding treatment and survival, a discordant present, which looked at the constraints and challenges of day-to-day functioning; uncertainty in managing disruptions on self and towards the future; and isolation, in relation to disconnect from self and relationships. Whilst this study contributed new knowledge to the field of cancer in relation to the substantive theory, only two accounts of men’s PCa experiences were noted. The PCa experience may differ significantly in comparison to other cancers. Analyses across studies showing the impact of differing cancers on men’s masculinity would have proved beneficial towards eliciting men’s perceptions of these experiences.

Stapleton & Pattison (2015) employed a phenomenological design to examine men’s experiences of advanced cancer and influence on masculinity. Similar to Wenger’s study, White men (n=8) diagnosed with different cancers were interviewed in the UK. Five emerging themes: thwarted ambition, changing expectations, protection and provision, stoicism and coping, images of illness versus images of masculinity, importance of being a fighter and loss; reflected men’s hegemonic masculinity attributes. Only 1 man diagnosed with PCa was among the study participants, which was not representative of this population.
In the remaining three studies that examined men’s experiences of PCa from a general perspective, one study utilized Bury’s framework of biographical disruption and liminality as biographical disruption (Navon & Morag, 2004) to explore the illness experience (Cayless et al., 2010). This will be further discussed in the review of theoretical literature.

Two studies utilized phenomenology to explore men’s experiences of PCa. Krumwiede & Krumwiede (2012) interviewed White men (n=10) between the ages of 62-70 years from the USA. Six emerging themes: living in the unknown, yearning to understand and know, struggling with unreliability of body, bearing the diagnosis of cancer, shifting priorities in the gap, and feeling comfort in the presence of other, reflected fears due to uncertainty, lack of knowledge and awareness related to all aspects of symptoms, diagnosis and treatment for PCa. Poor knowledge and distrust in the medical system was further highlighted when men asked questions relating to diagnosis during the interviews. This was due to uncertainty and unanswered questions experienced during care pathways. Although Krumwiede & Krumwiede (2012) did not highlight limitations of the study, some aspects related to masculinity that were present in the data were ignored. This was in relation to ‘embarrassment’ over purchasing urinary pads for incontinence; and the worry elicited over spousal abandonment due to ‘sexual dysfunction’. Moreover, the presenting excerpts provided were short and scarce. Most of the authors’ interpretations were not supported by data extracts. This can affect the trustworthiness of findings.

The other study that utilized a phenomenological framework (Salamo et al., 2016) is discussed in context of Radley’s illness representation framework in the review of theoretical literature. Nanton & Dale (2011) was the only one that investigated first generation Afro-Caribbean men (n=16) among the included studies. The sample site was in the UK. They explored men’s experiences of prostate disease and their perceptions of the services received utilizing in depth interviews. The ages of participants ranged from 50-83. The main purpose of the study was to identify if ethnicity played a significant role towards men’s experience. Through thematic analysis, these authors presented men’s PCa pathways as five constructs: Presentation and previous knowledge, diagnosis and decision making; treatment, care and side effects; informal support and social care; and knowing about PCa: living with PCa. These revealed a lack of information and knowledge throughout the trajectory of care pathways. Men also demonstrated silence regarding health problems during consultation with their GPs, such as incontinence and erectile dysfunction. Only men that were empowered with
information questioned HCPs for answers to problems. This was seen among the younger men. There was a demonstrated reluctance in taking advice from HCPs due to negative attitudes and discrimination experienced during interactions. Power imbalances in relationships were seen as barriers to asking doctors questions. Men’s belief systems were underlying all themes identified. For example, the authors interpreted men’s reticence as being connected to historical and cultural factors, such as limited and costly medical care and the strong influence of the ageing and vulnerability. This was demonstrated in the absence of knowledge in which men leaned to their personal, religious and family beliefs. This was evidenced in men’s use of complementary medicine and reported influence of religion in helping them to cope with the illness experience. Even though the sample size was not representative of the population, the findings contributed to BME literature regarding PCa experiences and possible constructs that may be relevant to similar ethnic groups.

2.2.14 Limitations of studies that broadly examined men’s PCa experiences

The research participants were predominantly White, from affluent populations and PCa patients were underrepresented in some studies (Wenger, 2013; Stapleton & Pattison, 2015). Findings were not representative of men’s experiences in relation to socioeconomic factors such as marital status, age, employment status, and cultural and ethnic backgrounds. Only two studies considered men’s beliefs and its influences (Nanton & Dale, 2011; Salomo et al., 2016). However, this was not explored in sufficient depth, inclusive of lay beliefs, culture and perceptions along care pathways to care. Only three studies were representative of African and Afro-Caribbean ethnicity (Anderson et al., 2013; Nanton & Dale, 2011; Salomo et al., 2016). One study sample interviewed younger men with PCa (Salomo et al., 2016). Only one study utilized a grounded theory framework and developed a substantive theory. However, this may not be a true representation since only two accounts of men diagnosed with PCa were provided (Wenger, 2013). Table 4 outlines studies included in the review that examined men’s experiences of PCa with broad aims.
<table>
<thead>
<tr>
<th>#</th>
<th>Author/year Country</th>
<th>Aim/Purpose (statement)/ Appropriateness of methodology/ Design of study</th>
<th>Theoretical framework/ Theory, Discipline,</th>
<th>Sample &amp; sampling strategy/data collection/saturation of data</th>
<th>Method of data analysis/description of data analysis/method of trustworthiness</th>
<th>Main findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Anderson et al., 2013 UK</td>
<td>To explore AAC men’s experiences of PCa and their understanding of its associated risks. The purpose was to gain an insight from these men’s perspectives and ascertain whether a more focused health promotion strategy, and specific UK-based research, was needed in this area.</td>
<td>Not stated</td>
<td>N=7; Aged 60-76 years African and Afro Caribbean men,</td>
<td>In depth face-to-face interviews</td>
<td>Braun and Clarke’s (2006) thematic conceptual analytical framework Details of methods of trustworthiness provided</td>
</tr>
<tr>
<td>2</td>
<td>Salamo et al., 2016 Namibia</td>
<td>To explore and describe the experiences of men diagnosed with PCa to have an understanding of what they go through and to compile guidelines for health workers to strengthen the support rendered to the patients.</td>
<td>None utilized</td>
<td>N=10; Aged 39-95 years African</td>
<td>Individual in-depth interviews; phenomenological, explorative and descriptive designs Tesch’s coding technique For analysis of data Measures for trustworthiness described</td>
<td>Rejection and isolation from family members and communities Lack of interpersonal communication and care from nurses Lack of knowledge and awareness of PCa Misconceptions related to PCa</td>
</tr>
<tr>
<td>#</td>
<td>Author/year Country</td>
<td>Aim/Purpose (statement)/ Appropriateness of methodology/ Design of study</td>
<td>Theoretical framework/ Theory, Discipline, (See theoretical Literature review)</td>
<td>Sample &amp; sampling strategy/data collection/saturation of data</td>
<td>Method of data analysis/description of data analysis/method of trustworthiness</td>
<td>Main findings</td>
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<tr>
<td>3</td>
<td>Cayless et al., 2010 Location not stated. However, authors are from UK</td>
<td>The aim is to provide an explanatory analysis of the liminal, ambiguous and chaotic experiences of men in this study, to outline the connexions with the concept of biographical disruption as described by Bury and to identify the implications for supportive care.</td>
<td>Bury’s biographical disruption and Navon &amp; Morag, liminality framework</td>
<td>N=10 Age and ethnicity of participants not stated</td>
<td>Three serial semi-structured interviews were conducted at (1) diagnosis, (2) treatment and (3) follow-up. These considered the three critical time points of the illness trajectory over the first year Descriptive and thematic analyses Details of rigor not provided</td>
<td>Accepting and expecting a diagnosis of PCa Treatment effects and disruptions Projected disrupted futures</td>
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<td>4</td>
<td>Chapple &amp; Ziebland, 2002 UK</td>
<td>Looks at the ways in which PCa and its treatment affect men’s perceptions of themselves, their bodies, their roles and sense of masculinity</td>
<td>Masculinity</td>
<td>N=52; Aged 52-80 years White British (N=48) Black Caribbean Black Nigerian Indian Czechoslovakian (n=4)</td>
<td>Unstructured interviews</td>
<td>Men’s health behaviour, the effects of treatment: incontinence, lack of energy, impotence Masculinity</td>
</tr>
<tr>
<td>5</td>
<td>Krumwiede &amp; Krumwiede, 2012 USA</td>
<td>To investigate the lived experience of PCa from a patient perspective.</td>
<td>A hermeneutic phenomenological approach</td>
<td>N=10; Aged 62–70 years. Caucasian</td>
<td>A hermeneutic phenomenological method using semi structured, open-ended questions ad-dressing the lived experience. van Manen’s method of inquiry and analysis Methods for details of rigor provided</td>
<td>Living in the unknown, yearning to understand and know, struggling with unreliability of body, bearing the diagnosis of cancer, shifting priorities in the gap, and feeling comfort in the presence of others. Fear and underlying lack of knowledge and awareness related to all aspects of symptoms, treatment; asking the researcher questions rather than the doctor (p 445)</td>
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<tr>
<td>Author/year Country</td>
<td>Aim/Purpose (statement)/ Appropriateness of methodology/ Design of study</td>
<td>Theoretical framework/ Theory, Discipline, Sample &amp; sampling strategy/data collection/saturation of data</td>
<td>Method of data analysis/description of data analysis/method of trustworthiness</td>
<td>Main findings</td>
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<td>6 Nanton &amp; Dale, 2011 UK</td>
<td>To investigate their experience of the disease and their perception of the services they have received. In relation to ethnicity</td>
<td>None utilized</td>
<td>N=16; Aged 50-83 years Afro-Caribbean men</td>
<td>One-to-one interviews were undertaken with first generation African-Caribbean men with a diagnosis of PCa. Coding &amp; thematic analysis</td>
<td>Lack of information and knowledge; silence of problems such as erectile dysfunction; questioning HCPs for answers to problems and reluctance in taking advice; discrimination with HCPs (negative attitudes); use of complementary medicine &amp; religion; power imbalance in relationships seen as a barrier to asking questions; men that were empowered especially younger ones questioned doctors</td>
<td></td>
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<tr>
<td>7 Wenger, 2013 Canada</td>
<td>This article helps attends to this gap by examining how men with a variety of cancers made sense of the challenges of their illness.</td>
<td>Gender lens framework/built a theory of the assaults of cancer</td>
<td>N=30; Age unknown White (n= 28), one was East Indian (n=1), Asian (n=1) Only 2 accounts stated from men diagnosed with PCa</td>
<td>Interviews, constructivist grounded theory approach</td>
<td>The ‘assaults’ of cancer. A troubled future A discordant present Uncertainty Isolation</td>
<td></td>
</tr>
<tr>
<td>8 Stapleton &amp; Pattison, 2015 UK</td>
<td>The aim of the study was to explore the lived experience of male patients with advanced cancer, including any description of events throughout the disease trajectory and treatment effects.</td>
<td>Masculinity lens</td>
<td>N=8; Aged 26–68 years all with advanced cancer, One PCA patient; ethnicity not stated</td>
<td>In depth interviews, A Qualitative approach using a Husserlian Phenomenological design; Colaizzi’s seven stage framework. Brief description of rigor</td>
<td>Thwarted ambition, changing expectations, protection and provision, stoicism and coping, images of illness versus images of masculinity, importance of being a fighter and loss.</td>
<td></td>
</tr>
</tbody>
</table>
2.2.15 Studies that examined the impact of the illness experience

Three studies investigated men’s experiences of PCa in relation to the impact of the illness via interviews. Frameworks utilized included phenomenology, cross-sectional postal survey and ethnography. The research perspective differed from the aforementioned studies in highlighting how men’s identity, psychological being and masculine embodiment were altered by prostate disease.

Baker et al., (2016) conducted semi-structured interviews with White patients (n=28) diagnosed with breast, lung and PCa in England to examine their views of the discontinuity or continuity of identity in the face of the cancer experience. A grounded theory was utilized. Ten PCa patients were among this sample. Four supporting excerpts representative of the PCa patients’ experiences were illustrated and are discussed here. The researchers highlighted participants’ experiences as three main themes. ‘Normality as continuity with the past’ described patients view of the cancer as disrupting their ‘old self’ and ‘an inconvenience’ As such they expressed a desire to return to their former biographical narratives and utilized personality traits such as ‘being a positive thinker’ and resisting the effects of cancer through positive ‘self-talk.’ This occurred among patients that were early in their cancer pathways prior to treatment. ‘Normality as a future discontinuous with the past’, reflected patients’ adjustment to the ‘new self’ in relation to the cancer diagnosis, treatment and side effects. Coexistence of different orientations to ‘normality’ was demonstrated among patients’ whereby they exhibited both the ‘old self’ and the ‘new self’ during the cancer trajectory. This mainly occurred among patients that had commenced treatment. The authors found no differences across patients and cancer stages. However, underlying all the elicited themes were personal and religious beliefs that were not explored in relation to discontinuity and continuity during care pathways. These may differ in relation to the cancer type, staging and at various stages in the care pathways. Nevertheless, the themes elicited in this study contribute to psychological and supportive care in demonstrating how patients cope during the cancer trajectory.

Even though one aim of Fitch et al., (1999) study was to highlight men’s perceptions (n=965) of the impact of PCa and treatment, a survey method is considered inappropriate to explore this phenomenon. Researchers conducted a cross sectional postal survey study to ascertain
Canadian men’s experiences. This covered a wide range of topics such as knowledge, treatment and perceptions regarding information and communication with healthcare professionals. The sample consisted of 95% White men with recurrent prostate disease. Although sexual function (50%) was highlighted as the most frequent problem occurring in men, followed by treatment side effects (35%), incontinence (25%), anger (14%), fear of dying (14%) and pain (14%); men received the lowest adequate help for this. Communication difficulties with healthcare professionals and dissatisfaction with information related to possible side effects of treatment, their medical condition, alternative therapies and psychosocial aspects, such as emotional reactions scored the highest percentage. Perceived impact on lifestyle and mental health were also reported. The survey did identify factors that impacted men’s physical and psychological well-being. However, an explorative approach may have elicited underlying issues such as the causation of anger and fear of dying; and factors contributing to communication with healthcare professionals. Additionally, the research sample was not adequately representative of the cultural diversity that exists in Canada. Including men from various ethnic groups would have enabled comparisons to be made across groupings.

The concept of masculine embodiment was captured in Kelly’s study, even though the sample size was small. Unlike Wenger’s study, the sample was better represented in relation to ethnicity and social status. Kelly (2009) utilized an ethnographic framework to explore men’s (n=14) masculine embodiment in relation to PCa, treatment and side effects. The sample was representative of men that were recently diagnosed with PCa, with the following demographics: Black men (n= 3); White men (n =5), sexual orientation (heterosexual n = 4; gay n= 1) and marital status (single n= 3; widowed n= 2). This paper focussed on the final stage of the illness experience. Seven themes were identified: living with a new body, diagnosis, restoring the masculine self, working with changed men, survival of the fittest, a new male identity and seeing other men in the world. These elicited how the disease, diagnostic procedures and side-effects of treatment impact men’s identity, sense of control and outlook. The impact of the illness experience manifested as blame, emotional isolation and feelings of shame and anger. Kelly did not illustrate which excerpts were associated with the varied demographics, neither did he highlight how the impact differed among the sample of men regarding ethnicity and social status. This can highlight variations within and across the sample, which can help to identify differences between traditional and other forms of
masculinity and associated beliefs. Table 5, which can be found on the following page shows the studies that were included in the review that examined the impact of the illness experience in men diagnosed with PCa.
<table>
<thead>
<tr>
<th>Author/year Country</th>
<th>Aim/Purpose (statement)/ Appropriateness of methodology/ Design of study</th>
<th>Theoretical framework/ Theory, Discipline</th>
<th>Sample</th>
<th>Method/data analysis</th>
<th>Main findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Baker et al., 2016 England</td>
<td>To examine views of continuity or discontinuity of identity in the face of cancer</td>
<td>Grounded theory</td>
<td>N=28; Aged 52-80 years White men</td>
<td>Semi-structured interviews</td>
<td>‘Normality’ as continuity with the past described patients’ ‘Normality’ as a future discontinuous with the past’ Coexistence of different orientations to ‘normality’</td>
</tr>
<tr>
<td>2 Fitch et al., 1999 Canada</td>
<td>To investigate the lived experience of PCa from a patient perspective.</td>
<td>Cross sectional study</td>
<td>N=965; Median age 69-70 White men 94%</td>
<td>Postal survey Descriptive statistics; statistical significance</td>
<td>Sexual function (50%) Treatment side effects (35%) Incontinence (25%) Anger (14%), Fear of dying (14%) Pain (14%); Communication difficulties with healthcare professionals Dissatisfaction with information</td>
</tr>
<tr>
<td>3 Kelly, 2009 UK</td>
<td>To investigate their experience of the disease and their perception of the services they have received. In relation to ethnicity</td>
<td>Ethnography Centrality of embodiment</td>
<td>N=14; Age not stated Black men, White men</td>
<td>Face-to-face interviews, observations, field work</td>
<td>Living with a new body, diagnosis, restoring the masculine self, working with changed men, survival of the fittest, a new male identity and seeing other men in the world.</td>
</tr>
</tbody>
</table>
2.2.16 Limitations of studies that examined the impact of PCa

Two of the three studies that represented men’s experiences in relation to the impact of PCa were conducted in the UK (Baker et al., 2016; Kelly, 2009). The samples for all studies were predominantly White, highlighting a dearth of research representative of diverse ethnicity. The ages of participants were representative of older men. Apart from Kelly’s study that highlighted the impact on masculinity (Kelly, 2009), personal and religious beliefs remain under researched. Only one grounded theory study was conducted, and a substantive theory was undeveloped (Baker et al., 2016).

2.2.17 Diagnosis experiences of men with PCa

Four studies investigated men’s diagnosis experiences of PCa (Halbert et al., 2010; Lehto et al., 2015; Korfage et al., 2006; Mathers et al., 2011). These studies highlighted other factors such as culture, emotions and patient-provider relationships that were not sufficiently examined in the aforementioned studies. However, only one study method was deemed appropriate to unearth men’s experiences (Mathers et al., 2011).

For instance, Halbert et al., (2010) conducted an observational study in Philadelphia utilizing structured telephone interviews among African American (n=70) and White (n=124) PCa patients to investigate men’s reactions to diagnosis. This choice of research design was one limitation of the study. Most of the men were diagnosed at stage T1 disease, with a Gleason score less than or equal to six and had a radical prostatectomy. Assessment of cultural factors, perceptions of social constraints and cancer-specific distress in addition to socio demographics and treatment status were obtained; and data analysed with descriptive statistics and bivariate analyses. Findings revealed that mostly younger and unmarried men that experienced moderate levels of cancer-specific distress and greater social constraints reported intrusive thoughts and feelings. This led to avoidance of friends and family and occurred mainly among men with greater perceptions of stress. Conversely, men with greater perceptions of confidence reported lower distress levels. Present temporal orientation was the only cultural factor that was associated with avoidance. This was reported among men that made more attempts to avoid intrusive thoughts and feelings. Whilst cancer-specific distress, present temporal orientation and social constraints occurred across ethnic groups,
the reasons underlying their occurrences may differ. These were not elicited in the study. Nevertheless, the ethnic diversity represented in the study was a major strength of the study.

Lehto et al., (2015) investigated men’s experience of their diagnosis at five university hospital districts in Finland via a survey questionnaire. The ages of men ranged from 44-94 years. Questions targeted men’s experiences of how they learned about the PCa diagnosis, by what means they selected treatment options, information received along care pathways, patient satisfaction and psychological reactions, which captured emotions at diagnosis. Findings showed that men reacted with uncertainty, shock, concern for their family future and fear of death and disability; and worry over if the cancer was treatable. Some men questioned why me whilst some felt no psychological upset and were relieved that the cancer was discovered in light of their symptoms experienced. Emotions experienced were mainly feeling blue and fluctuations in their mood. Others were bitter and angry and experienced wandering thoughts and grief. Worry and suicidal thoughts were still experienced at the time of the survey.

Most of the men were told the news of their diagnosis in an informal way, which contributed to dissatisfaction and affected their wellbeing. This was mostly via telephone and post, which occurred mainly among men whose anticipated treatment were brachytherapy and prostatectomy. However, men were informed via consultation with their doctors when the treatment of choice was hormonal therapy. The authors did not state possible reasons for this. Most of the men told their family about the diagnosis and some reported that this improved their relationships. Men reported varying levels of information and support via healthcare providers, the Internet, handouts, books, TV/radio and patient organizations. However, men that were university educated had very little support. The authors did not explore reasons for this. The study highlighted how significant effective communication and information needs are towards the diagnosis experience.

Similar to Halbert and Lehto research design, Korfage et al., (2006) conducted a prospective study among men between 55-74 years in the Netherlands to assess the impact of a PCa diagnosis on men’s mental health. The sample were asymptomatic men that participated in a PCa screening trial, with a Gleason score of less than or equal to seven. Men completed a health questionnaire via post (2 months before diagnosis), and two additional telephone questionnaires if subsequently diagnosed. These were prior to commencement of treatment and at six months post-diagnosis. The findings showed how the diagnosis of PCa had a
significantly negative impact on mental health. Data were analysed using paired t tests and unpaired t tests. Questionnaire scores (n=82) showed a significant decline in mental health at diagnosis, which improved at the initiation of treatment. The authors did not state how long men were enrolled in the programme, which may have implications for the impact on their mental wellbeing. The research design utilized may have drawbacks towards discovering other significant factors.

In relation to experiences of imaging procedures, Mathers et al., (2011) conducted a retrospective study in which men diagnosed with PCa (n=8) from cancer support groups participated. Men between the ages of 61-83 years participated in semi-structured interviews in North-East of Scotland. The focus of the interviews were presentation and referral; perceptions and experiences of the imaging tests; and imaging information and tests results throughout the care trajectory. Men that attended for annual health checks and requested PSA from their GPs, inclusive of those that experienced bone pains, nocturia and difficulty urinating were referred for scans. Men described receiving little and confusing information from their providers regarding imaging procedures but never questioned them. This was also related to conflicting information from different doctors. Some men believed that it was the doctor’s duty to provide information. This was also demonstrated by men’s reported faith in doctors. A few men that received information about their imaging procedures described feeling ‘a part of the team’ and ‘I knew what was happening for the first time’. Some men did not receive results of their imaging and had to request these from their GPs. Limitations identified were small sample size that was representative of the same geographical area. There was a dearth of information regarding men’s beliefs and perceptions of doctors, including their expectations of the information they should receive and underlying reasons for their faith in doctors. However, the findings shed light on men’s experiences of imaging procedures. Table 6 shows studies that were included in the review that examined men’s experience of PCa with a focus on their diagnosis.
### Table 6: Studies that examined the diagnosis experience in men with PCa

<table>
<thead>
<tr>
<th>Author/year Country</th>
<th>Aim/Purpose (statement)/ Appropriateness of methodology/ Design of study</th>
<th>Theoretical framework/ Theory, Discipline,</th>
<th>Sample &amp; sampling strategy/data collection/saturation of data</th>
<th>Method of data analysis/description of data analysis/method of trustworthiness</th>
<th>Main findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Halbert et al., 2010 Philadelphia, USA</td>
<td>To examine reactions to diagnosis.</td>
<td>Observational</td>
<td>N = 194; Age (average) 63 years African American (n=70) and White (n=124)</td>
<td>Observational study Telephone interviews Bivariate analysis</td>
</tr>
<tr>
<td>2</td>
<td>Lehto et al., 2015 Finland</td>
<td>To investigate patient experiences at diagnosis.</td>
<td>Observational</td>
<td>N=1239 Age: less than or equal to 64 (20%) More than or equal to 85 (5%) Ethnicity not stated.</td>
<td>Survey questionnaire Validated measures, descriptive statistics.</td>
</tr>
<tr>
<td>Author/year Country</td>
<td>Aim/Purpose (statement)/ Appropriateness of methodology/ Design of study</td>
<td>Theoretical framework/ Theory, Discipline,</td>
<td>Sample &amp; sampling strategy/data collection/saturation of data</td>
<td>Method of data analysis/description of data analysis/method of trustworthiness</td>
<td>Main findings</td>
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<tr>
<td>3 Korfage et al., 2006 Netherlands</td>
<td>To investigate patients’ experiences and psychological well being</td>
<td>Observational</td>
<td>N = 3800 55-74 years Ethnicity not stated</td>
<td>Questionnaire, telephone assessments Descriptive statistics; statistical analysis</td>
<td>Worsening of mental and self-reported health after diagnosis; scores significantly decreased after diagnosis.</td>
</tr>
<tr>
<td>4 Mathers et al., 2011 Scotland, UK</td>
<td>To explore the experience of people with a diagnosis of cancer while attending for imaging procedures.</td>
<td>Explorative</td>
<td>N = 8 PCa patients (support groups); Aged 61-83 years Ethnicity not stated</td>
<td>Semi-structured interviews Miles and Huberman analysis</td>
<td>Referral for scans- bone pains, nocturia, difficulty urinating, requested PSA test Men described receiving little and confusing information from their providers regarding imaging procedures but never questioned them. Conflicting information received from different doctors. Belief that it was the doctor’s duty to provide information/faith in doctors. Results of imaging not received.</td>
</tr>
</tbody>
</table>
2.2.18 Limitations of studies that examined men’s diagnosis experience of PCa

Studies that examined men’s experiences of diagnosis did not identify the ethnicity of participants, which can help contextualize differences across studies. Like other studies, the ages of men reflected an older age. Younger men were not represented in these studies to highlight their reactions and experiences of a PCa diagnosis. The research design utilized for most of these studies may have been unsuitable in relation to the aims of the study. A follow up qualitative design may have elicited rich data highlighting participants’ beliefs and meanings of the experience.

2.2.19 Post-diagnosis experiences of men with PCa

Three studies explored 3-8 months, the first year and two years post-diagnosis phase (Bradley et al., 2006; Jonsson et al., 2010; Wall et al., 2013). These highlighted men’s experiences of being diagnosed with localized and advanced stages of prostate disease. Younger men were represented in one study (Wall et al., 2013). In addition to the themes that were elicited in prior studies, the impact on work, daily living and similar underlying concepts such as masculinity and distress were found. However, men’s beliefs were overlooked.

In a study conducted in the USA, Bradley et al., (2006) highlighted absenteeism as a major impact of the PCa experience following (3-8 months) diagnosis. Telephone interviews were conducted at six months post-diagnosis among employed (n=206) men with an average age of 55 years. Men were primarily White, married and diagnosed with early stage prostate disease. Some of these men were not receiving treatment whilst others were being treated via surgery, hormone/radiation therapy and solely hormone therapy. The findings showed that men were absent from their jobs from 25-40 days. This was the same across all ages, ethnicity, employment status and marital status. Men receiving surgery in combination with other treatments experienced the most absenteeism, whilst those who had undergone radiation/hormone therapy without surgery experienced the least absenteeism. It was found that a leave of absence contributed to more absenteeism. Limitations identified in this study were in relation to the time frame following diagnosis, in which men may have adjusted to their diagnosis and treatment. The sample was representative of one geographical area, which may not reflect men’s experiences in other locations.
Researchers utilized a hermeneutic framework to conduct a longitudinal study that investigated whether PCa affects men’s (n=22) daily lives two years after the diagnosis in Sweden (Jonsson et al., 2010). Men that were diagnosed with localized and advanced PCa were interviewed (ages 50-85 years). The authors identified three equivalent fusions. ‘Age is claiming its due’, highlights men’s perceptions of their fatigue as related to ageing and not the disease. ‘Living with uncertainty’ describes men’s anxiety about their longevity in the face of illness. It also highlights their concern over the information given by healthcare providers and lack of knowledge about their condition. ‘Strengthen self-esteem’ illustrates men’s positive outlook in relation to being alive. This has enabled them to talk to other men about PCa amid their sexual dysfunction. The unifying fusion was identified as ‘balancing a changed life situation’. This describes how men value life day-by-day amid a PCa diagnosis. Spirituality played a major role in providing an ‘inner power’ towards men’s daily living, yet this was not adequately explored (Jonsson et al., 2010). Even though supporting excerpts were provided, these were not substantial in representing the entire sample. The researchers did not show how findings differed in relation to the staging of cancer, age and socioeconomic factors. Economical stability was highlighted, with supporting excerpts. It can be assumed that the sample of men was from an affluent population. Men of a lower socioeconomic background may have a different experience.

Some aspects of beliefs were explored in Wall’s study. Wall et al., (2013) conducted a constructive qualitative study that explored men’s experiences of localized PCa during their first year of diagnosis. Men from Australia (n=8) that received varying treatments between the ages of 44 and 77 years were interviewed in their homes. Data that reflected 3 months post diagnosis were analysed using constant comparison method. Five main categories emerged. Responding immediately describes men’s reaction of shock regarding their diagnosis of PCa. Their shock was due to the asymptomatic nature of the disease and lack of knowledge of this. Hiding distress reflects men’s stoicism in dealing with their emotions and hiding their vulnerability from others. Attenuating distress describes how men changed the focus of their distress to other matters, such as reflecting on life’s achievements, family and the presence of a higher power to cope. Minimizing the perceived
severity of PCa was a strategy used by men to cope with their diagnosis. They compared themselves to other men whom they perceived as ‘worse than mine’. The researchers felt that men were reticent about certain matters. *Talking about distress* highlights moments in which men spoke about something openly. Some men spoke to work colleagues about their cancer and explained how difficult it was for them to do so. However, most of the men remained silent about their distress. The authors did not state how these findings differed across the sample in relation to staging of cancer and treatment. Supporting excerpts reflected some aspects of men’s beliefs, which were not explored in depth (Wall et al., 2013). Studies that examined the post-diagnosis experiences of men are outlined in Table 7 on the following page.

### 2.2.20 Limitations of post-diagnosis studies

Similar to the prior studies, men’s ethnicities were not stated in two studies examining post diagnosis experiences. Men’s beliefs and perceptions were not adequately explored. One of the studies utilized telephone interviews (Bradley et al., 2006), which are deficient towards observing participants’ cues and body language (Opdenakker, 2006).
<table>
<thead>
<tr>
<th>Author/year Country</th>
<th>Author/year Country</th>
<th>Aim/Purpose (statement)/ Appropriateness of methodology/ Design of study</th>
<th>Theoretical framework/ Theory, Discipline,</th>
<th>Sample &amp; sampling strategy/data collection/saturation of data</th>
<th>Method of data analysis/description of data analysis/method of trustworthiness</th>
<th>Main findings/Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Bradley et al., 2006 USA</td>
<td>To examine the impact of PCa on absenteeism.</td>
<td>Epidemiological study</td>
<td>N=206 Predominantly White men Average age 55 years</td>
<td>Telephone interviews Mean and standard deviation; descriptive statistics</td>
<td>Men diagnosed with PCa missed an average of 27 days from work. The median days missed for men treated surgically without hormone or radiation therapy was 25. Taking a leave of absence and greater elapsed time from diagnosis to interview was associated with the greatest number of days absent from work for all patients. Men treated with hormone and/or radiation therapy or who were not treated missed fewer days from work relative to men undergoing surgery.</td>
<td></td>
</tr>
<tr>
<td>2 Jonsson et al., 2010 Sweden</td>
<td>To investigate whether PCa affects men’s daily lives two years after the diagnosis.</td>
<td>Hermeneutic framework Longitudinal study</td>
<td>N=22 50-85 years Ethnicity not stated</td>
<td>Face-to-face interviews Gadamer’s hermeneutics</td>
<td>‘Age is claiming its due’ ‘Living with uncertainty’ strengthen self-esteem’ ‘Balancing a changed life situation’.</td>
<td></td>
</tr>
<tr>
<td>3 Wall et al., 2013 Australia</td>
<td>To explore men’s experiences of localized PCa during their first year of diagnosis.</td>
<td>Constructivist inquiry</td>
<td>Age 48-77 years N=8 Anglo-Celtic</td>
<td>Home interviews Constant comparison</td>
<td>Responding immediately Hiding distress Attenuating distress Minimizing the perceived severity of PCa Talking about distress</td>
<td></td>
</tr>
</tbody>
</table>
2.2.21 Treatment experiences of men diagnosed with PCa

There were nine studies included in the current review that examined various aspects of men’s experiences of treatment for PCa. However, there remains a paucity of research that explores men’s beliefs and perceptions of experiences. In relation to active surveillance (AS), Berger et al., (2014) conducted a mixed methods study. A survey assessed characteristics associated with men’s decision to leave an AS programme in the USA. The qualitative design examined patients’ reactions to AS and experiences of those that left the programme respectively. Researchers found that mostly younger men self-elected to leave. Follow-up interviews with men (n=14) that opted to leave highlighted that they chose to participate in the AS programme because they felt that they had a twenty-five-year outlook and that follow-up would be beneficial towards relieving anxiety and delay treatment. However, they made a decision to leave because they wanted the cancer to be treated radically and perceived that it was best to commence earlier rather than with advancing age. Others were fearful that the cancer would metastasize, and they expressed their desire to be there for loved ones. The strength of this study was in the research design, which captured men’s beliefs and perceptions underlying their decisions. However, the research sample was predominantly White ethnicity.

In Norway, Ervik & Asplund (2012) interviewed men (n=10) that received endocrine therapy to explore their experiences utilizing a phenomenological framework. Men between the ages of 58-83 that received care from a university hospital participated. Five themes emerged. *Something is wrong,* reflects men’s awareness that they were being treated because of cancer. However, they reported a lack of knowledge about their treatment. They also stated that they received insufficient information from healthcare providers regarding the duration of the treatment and effectiveness. This was reported as, ‘nobody has told me that’. *When the body becomes troublesome* describes men’s bodily changes such as fatigue, decreased libido, and urinary leakage and challenges in managing these. *To be well or to be ill* reflects fluctuating periods of illness and wellness along the trajectory of care. *Dealing with the alterations* describes men’s use of optimism and humour to get through daily living. *To talk about cancer and the intimate details* illustrates men’s conversations with persons they perceived they could trust, such as their spouses, close friends and physicians who understood their concerns. Men felt talking to God and others were not useful and contributed to ‘low spirits’ (Ervik & Asplund, 2012). These perceptions were not explored in depth. The sample size was small, and the ethnicity was not stated. The authors attributed certain aspects, such
as sexual functioning to masculinity but did not explore other possible interpretations. For example, men highlighted certain concerns during the interviews but failed to ask their healthcare providers. Additionally, side effects linked to femininity, such as hot flashes may have affected men’s sense of masculinity. Beliefs were also underexplored, such as personal and religious beliefs and their influence on experiences.

The lived experiences of men (n= 20) receiving hormone ablation therapy were explored via in depth interviews utilizing a phenomenological framework in Australia (Ng et al., 2006). Men diagnosed with PCa that participated were between the ages of 50-70 and recruited from one research centre. Five themes were elicited. Discovering the disease refers to men’s, emotional reactions and misunderstandings when the disease was diagnosed. Whilst some men were symptomatic, others were not. Some men actively monitored their PSA and were prepared for a diagnosis of cancer whilst in others diagnosis of cancer was found incidentally. Decision-making dilemmas highlight men’s uncertainty and distress towards getting information and making decisions about treatment. Experiencing the effects of treatment describes men’s challenges with decreased libido, physical and psychological changes. Living with outcomes reflects how men’s sense of self was affected in relation to treatment regret and short-term and long-term goals and planning. Reaching toward health refers to physical and psychological strategies men adopted to be healthy such as diet, exercise and reading. The PSA result, information and support networks influenced patients’ coping strategies. Men reported that healthcare providers did not clearly explain certain information in sufficient detail, which affected their ability to cope. However, they acknowledged the importance of a supportive relationship with healthcare providers as significant to effective coping (Ng et al., 2006). The authors highlighted accounts of healthcare communication, but there is a dearth of exploration of beliefs surrounding men’s roles towards decision-making and their perceptions and expectations of healthcare providers’ roles.

Three studies examined men’s experiences of radiotherapy. Two of these solely focused on radiotherapy whilst the remaining study examined patients that received both radiotherapy and chemotherapy. Nevertheless, all three studies utilized a qualitative method of inquiry, and themes were similar in relation to information, knowledge and support. One of these studies highlighted certain aspects of beliefs (Smith et al., 2017), even though these were not explored in depth. Kelsey et al., (2004) conducted five focus group interviews with men diagnosed with PCa. These comprised of two groups of men (n=10) that received brachytherapy, and three groups of men (n=17) that received external beam radiotherapy.
Data were analysed using a thematic approach. Five themes emerged. ‘The journey to diagnosis’ describes men’s bodily changes and help seeking actions. Some men monitored their PSA and were referred for a prostate biopsy, which was described as ‘a necessary evil’. Others had a history of urinary tract infections and other urologic conditions.

Some men in Kelsey et al., (2004) study reported that the PSA test was taken by their GPs without their knowledge. Most of the men reported a desire to have more information at that time. ‘A satisfactory choice’ describes men’s lack of awareness and knowledge deficiencies regarding their treatment choices. This contributed to distress and uncertainty. Wives were present during treatment decision making but played little role towards this. Men in the brachytherapy group were more confident about their choice and described receiving more information about the procedure from their providers. ‘Experiences of radiotherapy’ reflect the discomfort from the procedure. Men also described use of humour to cope during treatment. ‘Support encountered’ describes the role of healthcare providers towards being there for men to ask questions; and partners’ and family’s role towards appointment scheduling and provision of care when side effects of treatment were experienced. These enabled men to cope. Dealing with the future describes the challenges men face in obtaining answers about their progress and long-term care. This was experienced mostly with junior staff members. Men reported not receiving answers to their questions and felt that providers were not straightforward with them about their concerns. The findings highlighted the significance of knowledge and information along the illness trajectory. However, only a few supporting extracts were provided, and men’s beliefs of their experiences were not explored in depth.

Smith et al (2017) utilized a framework analysis approach in which semi-structured interviews were conducted to explore patients’ (44-81 years old) experiences of radiation therapy in Australia. Five men diagnosed with PCa were among the sample recruited from radiation oncology departments. Four themes were elicited. ‘The decision to undergo radiation therapy’ reflects how patients follow their consultant’s advice because of their expertise and knowledge and the belief that they do so in the patients’ best interest. As such questioning was avoided even when they were concerned. This theme also described men’s choice of radiation therapy because of their belief that sexual functioning will improve. ‘Gaining knowledge and feeling informed’ describes challenges in understanding information. This was not experienced among university graduates. Some participants felt more confident if the
information via Internet was similar to what was received from treating doctors. However, some were not confident enough to search for information because of lack of knowledge of reliable sites. ‘Perceptions of care and support provided by the treatment team’ describe patients’ experiences of trust during treatment. ‘Strategies to enhance communication and support’ highlight healthcare providers’ role towards helping them use, interpret and understand information for their situation. Even though the sample size was small, some aspects of men’s beliefs and perceptions of experiences were demonstrated here. Researchers explored patients’ experiences of chemotherapy and radiation therapy via semi-structured interviews, in order to explore factors that influenced acceptance or refusal of treatment in Canada (Sattar et al., 2018). Eight men diagnosed with PCa were among the sample. Braun and Clarke thematic approach was utilized to analyse data. Four themes emerged which were related to decision-making and communication. In relation to decision-making, these themes were highlighted. ‘Trust in oncologist’ reflects patients’ choice as heavily influenced by the oncologist recommendation without questioning. ‘Prolong life’ highlights decisions for treatment based on perceptions of longevity. ‘Expected outcomes of treatment’ describe patients’ choices as influenced through perceived benefits. ‘Other people’s experiences’ highlight how other people influenced treatment-decisions. ‘Sceptical of going online’ describes participants’ fear that information might be confusing. ‘Assertion of independence’ describes how some men were autonomous in making decisions with available information, whilst others conformed to patriarchal style in wanting the doctor to make the final decision. In relation to communication, men felt that doctors were rushed, too busy and did not provide information in a caring, gentle and courteous manner. Some felt that this should be taken into consideration because they were elderly. Some patients felt resentment and an inconvenience because of poor communication. The presentation of excerpts was listed rather than followed by interpretations, which made it difficult to appraise. Beliefs and issues of masculinity were underexplored in this study. It was unclear which patients received chemotherapy and radiotherapy and how these experiences differed (Sattar et al., 2018).

A few studies explored men’s experiences of the prostatectomy as a primary treatment via interviews. In Canada, Milne et al., (2008) conducted focus group interviews and individual face-to-face interviews with men (n=19) within the ages of 48-76 years to explore their experiences 3-6 months following a laparoscopic radical prostatectomy. Using inductive analysis nine themes emerged. ‘Backgrounding oneself’ signifies the knowledge preparation that men pursued prior to their consultations. This was done through reading, browsing the
Internet and interacting with knowledgeable social contacts. They felt better able to understand the information received. ‘The benefit of early discharge’ illustrates that even though this procedure is associated with a reduced hospital stay, men expressed preference in staying longer due to pain and discomfort experienced. ‘Unexpected signs and symptoms’ describe men’s unanticipated reactions to side effects, such as gas pains, severe abdominal and bladder pain. Men were not prepared to cope with the discomfort from the catheter as represented by the category, ‘the sensory experience of catheterization’. ‘Coping with urinary incontinence’ describes the challenges men faced in relation to activities of daily living, such as travels and hobbies. ‘Is sex important?’ reflects the challenges men face with regard to erectile dysfunction, and an expressed desire for more information. ‘You’ve got to push yourself’ illustrate men’s determination in regaining their former self. ‘Having someone there’ describes men’s need for support throughout the illness trajectory. And, ‘entering a life of uncertainty’ depicts their concern about the disease progression and their future. Although timelines were illustrated for patients that were interviewed, no mapping of excerpts was done which would have enabled comparisons to be made between participants (Milne et al., 2008).

Researchers conducted interviews with men (n=8) that had undergone radical prostatectomy post 14 months to 15 years in Ireland (Walsh & Hegarty, 2010). Data were analysed using thematic content analysis. Six themes were highlighted. The process of diagnosis, support, normalisation, the importance of information, defining moments and primary concerns were similar to emerging themes from previous studies in relation to interactions with and role of healthcare providers, information giving and support. The sample size was small, and the authors did not highlight how men’s experiences differed in relation to length of time post prostatectomy. Nevertheless, men’s perceptions of communication with healthcare providers were highlighted.

In comparison to the previous study, Wennick explored men’s experiences of a prostatectomy at an earlier time frame, that is, 12-18 months of the procedure. Fear of cancer recurrence and death was one concept arising from this study that was similar to Walsh & Hegarty (2010) findings. This was significant in light of the 15-year interval post-prostatectomy; however underlying beliefs and perceptions related to this were not explored. Wennick et al., (2017) utilized an inductive approach in which men (n=19) that had an open or robotic radical prostatectomy were interviewed in Sweden (Wennick et al, 2017). Men were between the
ages of 49-65 years. Three themes were highlighted. ‘Paying a price for survival’ reflects men’s feelings of their post-treatment towards getting rid of the cancer and now being faced the side effects of treatment choices, such as loss of manhood, ‘Feeling sidestepped’ describes men’s perceptions of an uncaring health system and a society that view them as inferior to other cancers, such as breast cancer. ‘Living with death lurking around the corner’ illustrates men’s fear of cancer recurrence and subsequent death. Working and engaging in activities helped men cope with these fears. Some men felt alone because of these feelings. Hope was reported among men that believed in God. Belief in God contradicts Ervik & Asplund (2012) findings in which men felt talking to God contributed to low feelings. However, men’s beliefs about God may have impacted these feelings. These remain under researched. Table 8 shows the studies included in the review that examined treatment experiences of men diagnosed with PCa.

2.2.22 Limitations of studies that explored men’s treatment experiences

The BME population remains under represented in these studies. There is a scarcity of studies that explored underlying beliefs, perceptions and factors that impinge on men’s experiences of PCa. Most of the sample sizes for studies were small, and not representative of differing social and educational backgrounds.
<table>
<thead>
<tr>
<th>Author/year</th>
<th>Country</th>
<th>Aim/Purpose (statement)/ Appropriateness of methodology/ Design of study</th>
<th>Theoretical framework/ Theory, Discipline,</th>
<th>Sample &amp; sampling strategy/data collection/saturation of data</th>
<th>Method of data analysis/description of data analysis/method of trustworthiness</th>
<th>Main findings/Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Berger et al., 2014</td>
<td>USA</td>
<td>To examine patients’ reactions to active surveillance and experiences of those that left the programme respectively.</td>
<td>Mixed methods study</td>
<td>N=14 Age 40-80</td>
<td>Survey Semi-structured Interviews</td>
<td>Younger men self-elected to leave the active surveillance programme more than older ones</td>
</tr>
<tr>
<td>Ervick &amp; Asplund, 2010</td>
<td>Norway</td>
<td>To explore men’s experiences of endocrine therapy.</td>
<td>Phenomenological framework</td>
<td>N=10 Age 58-83 years</td>
<td>Interviews Phenomenology</td>
<td>Something is wrong When the body becomes troublesome To be well or to be ill Dealing with alterations To talk about cancer and the intimate details</td>
</tr>
<tr>
<td>Ng et al., 2006</td>
<td>Australia</td>
<td>To explore men’s experiences of hormone ablation therapy.</td>
<td>Qualitative framework</td>
<td>N=20</td>
<td>Interviews Phenomenology</td>
<td>Discovering the disease Decision-making dilemmas Experiencing the effects of treatment Living with outcomes Reaching toward health</td>
</tr>
<tr>
<td></td>
<td>Study Details</td>
<td>Methodology</td>
<td>Sample Size</td>
<td>Data Collection Methods</td>
<td>Major Findings</td>
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<td>4</td>
<td>Kelsey et al., (2004) UK</td>
<td>Qualitative</td>
<td>N=10 brachytherapy, N=17 external beam radiotherapy, Age not stated</td>
<td>Focus group interviews, Thematic analysis</td>
<td>The journey to diagnosis, A satisfactory choice, Experiences of radiotherapy; 4 support encountered, Dealing with the future</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>Milne et al., 2008 Canada</td>
<td>Qualitative descriptive method</td>
<td>N=19, 48-76 years</td>
<td>Face-to-face interviews, Inductive/thematic analysis</td>
<td>Backgrounding oneself, The benefit of early discharge, Unexpected signs and symptoms, The sensory experience of catheterization, Coping with urinary incontinence, ‘Is sex important?’ You’ve got to push yourself, Having someone there, Entering a life of uncertainty</td>
<td></td>
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<tr>
<td>6</td>
<td>Smith et al., 2017 Australia</td>
<td>Framework analysis</td>
<td>N=5, 44-81 years</td>
<td>Semi-structured interviews</td>
<td>The decision to undergo radiation therapy, Gaining knowledge and feeling informed, Perceptions of care and support provided by the treatment team, Strategies to enhance communication and support</td>
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<td></td>
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<td>Country</td>
<td>Objective</td>
<td>Methodology</td>
<td>Sample Details</td>
<td>Data Collection</td>
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<td>7</td>
<td>Sattar et al., 2018</td>
<td>Canada</td>
<td>To explore factors that influence acceptance or refusal of treatment.</td>
<td>Braun &amp; Clarke thematic approach</td>
<td>N=8 66-78 years</td>
<td>Semi-structured interviews</td>
</tr>
<tr>
<td>8</td>
<td>Walsh &amp; Hegarty, 2010</td>
<td>Ireland</td>
<td>To provide a retrospective view of men’s experiences of the PCa treatment journey from initial diagnosis through to completion of their surgery and beyond.</td>
<td>Qualitative descriptive design</td>
<td>N=18 Ethnicity not stated Age not stated</td>
<td>Interviews Thematic content analysis</td>
</tr>
<tr>
<td>9</td>
<td>Wennick et al., 2017</td>
<td>Sweden</td>
<td>To explore men’s experiences of an open or robotic prostatectomy at 12-18 months.</td>
<td>Descriptive qualitative Inductive approach</td>
<td>N=19 49-65 years Ethnicity not stated</td>
<td>Interviews Thematic content analysis</td>
</tr>
</tbody>
</table>
2.2.23 Couples experiences of PCa

Six studies that were included in the review explored couples’ experiences of PCa. These are outlined in Table 9. One study focused on the impact of the illness on couples’ relationships (Harden et al., 2002). Some were in relation to diagnosis and treatment (Gray et al., 2000a), treatment decision-making (Boehmer & Clarke, 2001a; O’ Callaghan et al., 2014); aspects of care (Sinfield et al., 2008); and the impact of knowledge and awareness along care pathways (Docherty et al., 2007). Whilst the findings of these studies stated those partners’ supported men along care pathways for PCa, an exploration of their roles remains under researched. Themes highlighted in these studies are similar to studies that solely examined men’s experiences, with the exception of partners’ accounts. These were related to relationships, coping, support, treatment decision-making and managing the impact of the illness on daily living and emotions.

A study conducted six (men=22; spouses=20) focus groups (Harden et al., 2002) in the USA to explore couples’ experiences of PCa. A cognitive-appraisal model of stress was used as a framework. The sample consisted of mainly White men (64%) and women (75%). Four themes were elicited. ‘Enduring uncertainty’ describes the conflicting information received from healthcare professionals regarding treatment and confusion towards their life plans because of the disruptive effects of a cancer diagnosis and treatment. ‘Living with treatment effects’ highlights the urinary, sexual bodily changes and mood fluctuations that occurred and the distress these created for couples. ‘Coping with change’ describes the intrusion of the cancer and treatment on day-to-day activities, and measures couples implemented to manage these. Some couples decided not to disclose the diagnosis with families, whilst others shared with church members for support. Some wives were told not to ask their doctors any questions. They also stated that their husbands did not involve them in their care. Anger and physical distress were elicited from wives about the situation. ‘Needing help’ highlights couples’ dependence on healthcare staff, information and peer support. They felt that healthcare professionals were distant and uncompassionate; and follow-up were ignored, with the exception of one nurse who made time for concerns. Couples felt that information was not provided, adequate time was not given to address concerns and questions remained unanswered because staff appeared busy. They longed for someone to talk to, such as a sponsor. The study provided supporting data; however, it was not apparent which excerpt belonged to ethnic groups. Additionally, beliefs were not explored in depth in this study.
Whilst the previous study focused broadly on couples’ experiences, Gray’s study examined their journey at three specific points in relation to men that were awaiting prostatectomy. Gray et al., (2000a) conducted a longitudinal qualitative study in which White men (n=34) diagnosed with PCa and their spouses in Canada were interviewed at three points: before prostatectomy surgery, 8-10 weeks and 11-13 months following prostatectomy surgery. Ages of men ranged from 50-68 and their spouses 42-72 years. Data was analysed using constant comparison. The core category, ‘managing the impact of illness’ emerged. This describes how couples utilized multiple strategies in order to maintain control of and prevent the cancer from disrupting their lives. This was reflected via five domains. ‘Dealing with the practicalities’ highlights couples’ experiences of the diagnosis of cancer, and how they coped with sourcing information and decision-making.

Most men in Gray et al., (2000a) study were diagnosed via a routine check-up (PSA and DRE). Men reported not receiving sufficient information from their GPs in relation to abnormal PSA tests and a lack of referral. Knowledge deficiency in relation to treatment options was also reported. However, couples searched the Internet and participated in support groups as a means of obtaining information. This domain also addresses men’s effort to lose weight prior to surgery through dieting and exercising; and managing and coping with stressors in the midst of this. ‘Stopping illness from interfering with everyday life’ reflects how couples tried to minimize the disruption of the diagnosis of PCa and treatment through non-disclosure and continuing with normal activities. ‘Keeping relationships working’ describes how couples tried to be strong for each other and work as a team whilst not allowing the illness to be the focus. ‘Managing feelings’ highlights the emotions invoked by the illness experience such as anger and shock. Some men isolated themselves in order to adapt. Communication between couples were optimal for some whilst for others, this was affected. And, ‘making sense of it all’ describes how couples made meaning of their experiences in relation to the illness, outlook on life and preparations for possible death. Some aspects of the data could have been interpreted as masculinity, even though this was not elicited. Additionally, the roles women portrayed, and their beliefs and perceptions of their experiences were not adequately examined.

In relation to men diagnosed with metastatic cancer, researchers conducted separate focus group interviews with men (n=7) and their wives to explore perceptions of their PCa diagnosis
and roles towards treatment decision-making (Boehmer & Clarke, 2001a). The participants were from the USA and were between 61-75 years old and were representative of White and Black ethnic groups. They were receiving varied treatments. Data were analysed using Strauss and Corbin’s grounded theory framework. In relation to the diagnosis and treatment decision-making, the husbands’ accounts differed to their wives in that they did not speak of their wives’ involvement. However, their wives mentioned how they were instrumental towards motivating their spouses to see a doctor.

It was found that men in Boehmer & Clarke (2001a) study did not disclose their bodily changes with their wives and delayed medical help seeking even though they experienced urinary changes and impotence. This was due to perceptions that symptoms were related to ageing and temporal. Men consulted their doctors when symptoms became debilitating. The wives focussed on when the cancer was discovered and how they were instrumental towards motivating their spouses to see a doctor. With regards to treatment decision-making, a triadic interaction between the doctor, spouse and wife was elicited. In the first interaction, the wives were excluded from conversations about treatment decision-making that occurred between the doctor and the patient. This was due to men’s preference for the treating doctor to make decisions for them. Wives were never invited to be a part of treatment decision-making and they perceived that their opinions did not matter. The second interaction describes how physicians prompted wives’ involvement towards their husbands’ treatment decision-making in situations whereby men were frail or in which communication was difficult. The third type of interaction describes the partnership between the husband and wife towards treatment decision-making; however, the role of the physician is either challenged or succumbed to. Couples perceptions in relation to ethnic variations, staging of prostate disease and socioeconomic factors were not explored. Beliefs and perceptions related to partners’ involvement in treatment-decision-making was ignored. For example, factors influencing partners beliefs regarding them not being invited to consultation with their spouses were not investigated (Boehmer & Clarke, 2001a).

Partners’ feelings of disregard were also elicited in a study conducted in Australia. However, the research design was not deemed appropriate towards exploring underlying factors. Men (n=21) and their partners’ (n=14) experiences of decision making in relation to active surveillance (AS) as the recommend treatment choice for localized PCa was examined via
semi-structured telephone interviews (O’Callaghan et al., 2014). The sample consisted of two groups of men: those that declined AS in favour of radical treatment and men who started this type of treatment approximately three months ago. All men were diagnosed with stage II and III PCa that were recruited from both private and public practice. Data were analysed utilizing principles of grounded theory. The results highlighted themes related to information, decision-making, shared experiences, coping, monitoring, stressful factors and discontinuation of AS. Couples reported contradictory, confusing and misunderstanding of information received from healthcare providers, which contributed to distress. Some men reported receiving unanswered medical questions from healthcare providers, and some did not ask questions even though they were concerned about treatment. However, men asked questions during the interviews. Men voiced challenges over making decisions about AS. These pertained to relatives and partners opposing views of the AS due to perceptions that this was not effective, and preference for the radical prostatectomy. Partners supported their spouses even though they felt disregarded because they were not invited in treatment decision-making consultations. Couples utilized coping strategies such as positive self-talk and were happy with trusted healthcare professionals during monitoring. However, men reported painful biopsies and fear of disease progression while on AS. This influenced some of them to consider radical treatment. The findings highlighted the challenges couples faced, however, beliefs and perceptions of the experiences were under explored. For example, reasons why men did not question healthcare providers but did so with the researchers were not investigated. The authors highlighted that partners were supportive towards monitoring appointments but did not explore other roles.

Docherty et al., (2007) explored both patients and spouses’ experiences of PCa from the initial symptoms to treatment, with a focus on the impact of knowledge and awareness. Two focus groups (5 men and 1 woman; 4 men and 2 women; 54-79 years) were conducted via an independent support group in the UK. Data were analysed using a thematic approach. Four main categories emerged. ‘The initial experience’ portrays the couples’ lack of knowledge and awareness of the workings of the prostate and symptoms indicative of PCa. These contributed to their shock when diagnosed with prostate disease. Men delayed help seeking because they attributed urinary symptoms to ageing and were uncertain about the meaning of their bodily changes. Wives influenced men’s help seeking behaviours. Couples highlighted the significance of the GPs role towards the provision of information, tests and referral. ‘Patient involvement’ describes the proactive role of couples towards making contact with healthcare
staff. Women were instrumental in obtaining information for their spouses. Men opted for treatment that did not affect sexual intercourse, and others decided to purchase private healthcare when they experienced diagnostic and treatment delays. In relation to the category, ‘health judgement’ reflects the perceptions that most men held towards their health. They described feeling well in light of their diagnosis of cancer. ‘Coping’ elicited men’s strategies in dealing with the cancer diagnosis through purchasing private healthcare to commence treatment quickly and comparing themselves to others, as seen in Wall’s study. The sample sizes were small, and the authors did not identify how the findings differed in relation to staging of disease, treatment and socioeconomic factors. Only one role towards sourcing information was highlighted in relation to partners. The study did not highlight participants’ beliefs.

Partners’ perceptions of disregard remain a recurring theme in the literature and have emerged among separate samples and ethnicities in various countries. Sinfield et al., (2008) study conducted semi-structured interviews with men (n=35) that were mostly over 70 years, diagnosed with PCa and their female partners (n=10) in England to investigate their experiences of care. The sample consisted of White (n=26), Afro-Caribbean (n=5) and South Asian (n=4) men that received varied treatment, and White (n=8), Afro-Caribbean (n=1) and South Asian (n=1) female partners. Data was analysed utilizing a framework approach. With the exception of one man that participated in a trial, couples reported a deficiency towards receiving information from healthcare providers. This contributed to anxiety, shock and a lack of knowledge. Men reported not being told that they were tested for PCa and an inability to understand the medical jargon used. This lack of information pertained to symptoms of prostate disease, diagnostic tests, such as the prostate biopsy, and treatment decision-making. Men also experienced a lack of communication with healthcare providers. This was reported as, ‘the doctor was talking to himself’, lack of privacy in giving information, such as in the waiting room in front of other patients and being given the wrong diagnosis. Couples reported that partners were not invited by physicians to attend consultations, even though they still attended and felt disregarded. However, partners took an active role in asking questions even when they perceived this was not welcomed. The authors did not identify how findings differed across ethnic groups, and according to treatment. However, the findings highlighted the importance of information and knowledge and the role of the patient, the healthcare provider and partners towards decision-making.
2.2.24 Limitations of studies that explored couples’ experiences of PCa.

Similar to previous included studies, most samples were small and not representative of diverse ethnicity (Harden et al., 2002; Gray et al., 2000a), and one research design was not applicable in relation to the aims of the study (O’Callaghan et al., 2014).
<table>
<thead>
<tr>
<th>Author/year Country</th>
<th>Aim/Purpose (statement)/ Appropriateness of methodology/ Design of study</th>
<th>Theoretical framework/ Theory, Discipline,</th>
<th>Sample &amp; sampling strategy/data collection/saturation of data</th>
<th>Method of data analysis/description of data analysis/method of trustworthiness</th>
<th>Main findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Harden et al., 2002 USA</td>
<td>To explore couples’ experiences of PCa</td>
<td>Cognitive appraisal stress model.</td>
<td>Men (n=22) Women (n=20) Predominantly white ethnicity Ages 40-90</td>
<td>Focus group interviews</td>
<td>Enduring uncertainty Living with treatment effects Coping with change Needing help</td>
</tr>
<tr>
<td>2 Gray et al., 2000a Canada</td>
<td>To explore men and partners’ experiences before prostatectomy surgery, 8-10 weeks and 11-13 months following prostatectomy surgery.</td>
<td>Qualitative longitudinal study</td>
<td>N=34 Ages 50-68 White ethnicity</td>
<td>Interviews Grounded theory</td>
<td>The core category, managing the impact of illness Dealing with the practicalities Stopping illness from interfering with everyday life Keeping relationships working Managing feelings Making sense of it all</td>
</tr>
<tr>
<td>3 Boehmer &amp; Clarke, 2001a USA</td>
<td>To explore perceptions of their PCa diagnosis and roles towards treatment decision-making.</td>
<td>Grounded theory framework</td>
<td>N=7 Ages 61-75 years White and Black ethnicity</td>
<td>Focus group interviews Strauss &amp; Corbin grounded theory analysis</td>
<td>Non-disclosure of bodily changes to wives Delay in medical help seeking even though they experienced urinary changes and impotence; trigger: debilitating symptoms Perceptions: ageing and temporal. The wives focussed on when the cancer was discovered and how they were instrumental towards motivating their spouses to see a doctor. A triadic interaction between the doctor, spouse and wife was elicited.</td>
</tr>
<tr>
<td>Author/year Country</td>
<td>Aim/Purpose (statement)/ Appropriateness of methodology/ Design of study</td>
<td>Theoretical framework/ Theory, Discipline,</td>
<td>Sample &amp; sampling strategy/data collection/saturation of data</td>
<td>Method of data analysis/description of data analysis/method of trustworthiness</td>
<td>Main findings</td>
</tr>
<tr>
<td>---------------------</td>
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</tr>
</tbody>
</table>
| 4 O’Callaghan et al., 2014 Australia | To examine couples’ experiences of decision making in relation to active surveillance (AS) as the recommend treatment choice for localized PCa. | Qualitative research design | Men (n=21)  
Partners (n=14)  
Ages less than 40-over 90  
The sample consisted of two groups of men: those that declined AS in favour of radical treatment and men who started this type of treatment approximately three months ago. | Telephone interviews  
Grounded theory | Distress related to information, decision-making, shared experiences, coping, monitoring, stressful factors and discontinuation of AS. |
| 5 Docherty et al., 2007 UK | To explore both patients and spouses’ experiences of PCa from the initial symptoms to treatment, with a focus on the impact of knowledge and awareness. | Qualitative design | Men (n=9)  
Women (n=3)  
Focus group #1 (5 men, 1 woman)  
Focus group #2 (4 men, 2 women)  
Ages 54-79 | Focus group interviews  
Thematic approach | Initial experience  
Patient involvement  
Health judgement  
Coping |
| 6 Sinfield et al., 2008 UK | Experiences of care | A framework approach | N=35 men, women n=10; over 70 yrs.  
White, Afro-Caribbean, South Asian | Semi-structured interviews  
Thematic analysis | Lack of knowledge  
Poor communication with healthcare providers  
Partners’ perceptions of disregard |
2.2.25 Partners’ experiences of PCa

Three studies examined partners’ experiences of PCa in relation to daily living (Ervik et al., 2013), their understanding of spousal experiences of the disease and subsequent treatment (Carlson et al., 2001; Wootten et al., 2014). These studies are outlined in Table 10 (p. 98). Masculinity was illuminated in supporting excerpts, yet this was not interpreted as this concept (Ervik et al., 2013). Researchers assert that partners’ have been supportive but there is a deficiency in highlighting their roles and a comprehensive understanding of beliefs and perceptions of these experiences (Carlson et al., 2001; Wootten et al., 2014).

Researchers conducted in depth interviews with partners (n=9) in Norway, utilizing a phenomenological approach to explore how their daily lives were affected by their spouses’ diagnosis of PCa (Ervik et al., 2013). Men had been treated with surgery, radiotherapy and hormone therapy. Four themes emerged which reflected the emotional and practical impact of the disease on partners. ‘Strong and optimistic versus vulnerable and overstrained’ describes how partners suppressed their anxieties and affect in order to demonstrate love and support throughout the trajectory of treatment. ‘Maintaining the partner’s sense of manhood’ reflects challenges in adjusting to sexual dysfunction. Partners reported that men remained silent about intimate details. As such partners were cautious towards exposing their husbands and were tactful in their conversations during interviews. ‘Being on the sideline’ describes the priority placed on the husband because of the disease, and the insignificance partners’ felt from friends, family and healthcare providers. ‘The need for relationships outside the immediate family’ illustrates how partners longed to discuss the impact of the illness to others in order to cope. Even though the sample size was small, and the ethnicity was not stated, the findings showed how partners need for support is critical during the course of the illness.

Partners’ support was also stated in a mixed methods study that utilized a questionnaire and semi-structured interviews (Carlson et al., 2001). Researchers investigated partners’ understanding of their spouses’ experience of PCa. Fifteen couples that were approximately 67 years old participated in the study. Data was analysed via statistical evaluation. The partners had a good understanding of their husbands’ experiences and provided support in relation to attending appointments. They also reported satisfaction with support. The illness experience affected partners’ more than their spouses. There is insufficient depth in
highlighting the roles partners’ play and how the illness experience impacts them. Additionally, partners’ beliefs and perceptions of their experiences are vague.

The issue of masculinity was highlighted in a Wootten’s study. Focus group interviews were conducted with partners (n=27) of men diagnosed with PCa in Australia. Partners were 43-76 years old and their spouses received varied treatments. Data were analysed via a thematic approach (Wootten et al., 2014). Six themes were elicited across all treatment cohorts. ‘The influence of the man’s response to PCa on the partner’ captured the impact of men’s coping responses on their partners’ well-being. For example, partners had lower levels of distress when their spouses coped positively. Conversely, partners had higher levels of distress when their spouses demonstrated poor coping skills. ‘The need to be involved in treatment and medical decision making’ reflected couples’ access to information. Emotionally distressed couples were not confident and self-motivated to access information in comparison to couples that were not. ‘Supporting a man who is experiencing a loss of masculinity’ described the communication challenges couples faced in relation to a loss of sexual function. ‘Degree of congruence between each partner’s coping responses’ described three varied strategies that were present: some couples were both positive, negative or mainly partners were optimistic about the impact of PCa. ‘Constrained communication’ described challenges couples faced in relation to intimacy and diagnosis disclosure. ‘Changed roles and increased practical management’ illustrated partners’ challenges towards supporting their spouse while balancing personal and financial responsibilities. The ethnicity of participants and socioeconomic backgrounds were not stated, which helps identify unique differences. The authors did not explore partners’ personal beliefs of their experiences, which can contextualize how these influenced their experiences.

2.2.26 Limitations of studies that explored partners’ experiences

The authors identified the small sample size as not being representative of the population. Partners’ perceptions of masculinity remain under researched, including their roles along care pathways for PCa. There is a need for ethnic diversity sampling to bring light to a wide range of views from partners’ perspective. Also, a representation of partners’ experiences of PCa from various geographic locations is lacking. This can highlight similarities and differences across groups of women.
<table>
<thead>
<tr>
<th>Author/year Country</th>
<th>Aim/Purpose (statement)/ Appropriateness of methodology/ Design of study</th>
<th>Theoretical framework/ Theory, Discipline,</th>
<th>Sample &amp; sampling strategy/data collection/saturation of data</th>
<th>Method of data analysis/description of data analysis/method of trustworthiness</th>
<th>Main findings/Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Ervick et al., 2009 Norway</td>
<td>To explore how the daily life of female spouses is affected by their husband’s PCa.</td>
<td>Hermeneutic phenomenology</td>
<td>N=9 Ages 52-68 Ethnicity not stated</td>
<td>In-depth interviews</td>
<td>Strong and Optimistic Versus Vulnerable and Overstrained Maintaining Partners’ Sense of Manhood Being on the Sideline Need for Relationships Outside the Immediate Family</td>
</tr>
<tr>
<td>2 Carlson et al., 2001 Canada</td>
<td>To examine partners’ understanding of patients’ experience with prostate or breast cancer and to assess the congruence between patient and partner perceptions regarding social support and the cancer experience.</td>
<td>Exploratory design</td>
<td>N=15 couples (PCa Approximately 67 years old Ethnicity not stated</td>
<td>Profile of Mood States (POMS) questionnaire (statistical analysis) Semi-structured interviews (Likert-scales)</td>
<td>Partners possessed an accurate understanding of their husbands’ experience with PCa and perceptions regarding social support in the relationship were congruent. This was associated with the length of marriage. Partners were having a bit more difficulty with the experience than their spouses.</td>
</tr>
<tr>
<td>3 Wooten et al., 2014 Australia</td>
<td>To explore the experiences of intimate spouses or partners of men diagnosed and/or treated for PCa to better understand the personal impact of PCa on the partner.</td>
<td>Qualitative design</td>
<td>N=27 partners Ages 43-76 years Ethnicity not stated</td>
<td>Six focus group interviews One structured interview Thematic analysis</td>
<td>The influence of the man’s response to PCa on the partner The need to be involved in treatment and medical decision making Supporting a man who is experiencing a loss of masculinity Degree of congruence between each partner’s coping responses Constrained communication Changed roles and increased practical management.</td>
</tr>
</tbody>
</table>
2.2.27 Knowledge deficiencies, lack of awareness and uncertainty

Men and partners demonstrated knowledge deficiencies, lack of awareness and uncertainty of PCa pre-diagnosis and along care pathways to treatment. In relation to the pre-diagnosis and diagnosis trajectory, some men associated PCa with the colloquial term ‘stoppage of water’ in the community but their knowledge of the disease was limited (Nanton & Dale, 2011). Most men became aware of the prostate gland and the disease through social contacts. They were not aware of the asymptomatic presentation of early stage prostate disease (Anderson et al., 2013; Cayless et al., 2010; Ng et al., 2006). Those that were symptomatic could not make connections with PCa and were unaware of the significance of symptoms experienced (Anderson et al., 2013, Cayless et al., 2010, Docherty et al., 2007; Sinfield et al., 2008; Walsh & Hegarty, 2010). A few men that had a little knowledge expressed suspicions and doubt regarding the high incidence among African men (Anderson et al., 2013). Men possessed knowledge of the DRE, however the significance of the PSA test was deficient (Mathers et al., 2011). In fact, some men were unaware that their GPs had taken a PSA blood sample until they were diagnosed with the disease. Men lacked knowledge about PCa prior to diagnosis (Nanton & Dale, 2011; Anderson et al., 2013; Salomo et al., 2016) and voiced uncertainty about the presence of cancer in their body due to distrust in the medical system. One man that had a prostatectomy, for instance was told he had no cancer and was subsequently diagnosed with cancer. Due to his experience, he felt that he was misdiagnosed (Krumwiede & Krumwiede, 2012). Other studies also highlighted men’s perceptions and experiences of misdiagnosis (Wenger, 2013). Uncertainty and ignorance ensued during diagnostic procedures and treatment. Men lacked knowledge of diagnostic and treatment procedures, treatment and related-side effects and complications. This was found across all treatment types, including active surveillance, radiotherapy, chemotherapy and hormonal therapy (Berger et al., 2014; Boehmer & Clarke, 2001a; Ervik & Asplund, 2012; Harden et al., 2002, Jonsson et al., 2010; Kelsey et al., 2004; Milne et al., 2008; Sinfield et al., 2008; Smith et al., 2017; Walsh & Hegarty, 2010; Wootten et al, 2014).

Except for university educated men, reasons highlighted were a lack of information and explanation received from healthcare providers, the inability to understand medical jargon via communication with doctors and in written material; unavailability of material (further discussion under communication). These barriers caused men to feel unprepared for the discomfort arising from the prostate biopsy and catheterization. Some men were proactive in obtaining information about their treatment prior to consultation as a means of preparation and comparison (Sattar et al., 2018, Smith et al., 2017). Men gained knowledge of treatment through other men diagnosed with PCa, which
helped them compare symptoms and cope (Krumwiede & Krumwiede, 2012). Uncertainty was also experienced in relation to the future across all studies among men that received various treatments. This was related to the possible recurrence of cancer, treatment side effects and quality of life. Two studies highlighted that men’s lack of knowledge of PCa may have been attributed to an eventful and busy hospital (Harden et al., 2002; Nanton & Dale, 2011). Although this argument may be true, questions such as what men’s beliefs of their experiences are remain unanswered.

2.2.28 Poor communication, distrust and lack of support in healthcare

Coupled with disease-specific stress and the mental impact of diagnosis evidenced as intrusive thoughts, social constraints and present temporal orientation men were faced with poor communication and a lack of support during diagnosis and post diagnosis, which made their experiences overwhelming (Korfage et al., 2006, Halbert et al., 2010). Men recalled not being offered a PSA test by their GPs prior to their diagnosis of cancer (Ervik & Asplund, 2012, Mathers et al., 2011), not being told that a PSA blood test was done (Walsh & Hegarty, 2010). And those that requested PSA testing stated that their GPs did not inform them about the significance of this (Walsh & Hegarty, 2010), and that this was not reliable in detecting PCa (Ervik & Asplund, 2012). In another study, a man who experienced bone pain stated that his request for a scan was turned down by his GP, which contributed to resentment and distrust when diagnosed with PCa (Mathers et al., 2011).

Participants reported dissatisfaction and insensitivity towards receiving the news of cancer (Lehto et al., 2015), poor communication skills and lack of privacy (Lehto et al., 2015, Sinfield et al., 2008). For example, one man stated that before he could sit the doctor had told him they found cancer (Walsh & Hegarty, 2010), information was given in the waiting room in front of others rather than in the office (Sinfield et al., 2008), and over the phone (Lehto et al., 2015). Others described crudeness (Lehto et al., 2015) and doctors muttering to themselves rather than talking openly with them, which led to feelings of distrust (Sinfield et al., 2008). It was found in one study that patients whose intended treatment was radiotherapy were more likely to receive their diagnosis over the phone rather than patients that would receive hormonal therapy (Lehto et al., 2015). Information provided during diagnosis was described as inappropriate time to ‘absorb’ (Mathers et al., 2011). Men that experienced delays along care pathways decided to purchase private healthcare (Docherty et al., 2007).

Even though men reported faith and trust in healthcare providers because of their expert knowledge (Smith et al., 2017), poor communication contributed to perceptions of an uncaring health system
(Milne et al., 2008; Nanton & Dale, 2011; Harden et al., 2002; Walsh & Hegarty, 2010; Wennick et al., 2017). These contributed to feelings of distrust and disconnect (Sattar et al., 2018) in healthcare. Apart from the aforementioned reasons, distrust was experienced when staff did not attend to men in a timely manner and were clinical or ‘distant’ (Milne et al., 2008) in their communication (Nanton & Dale, 2011, Harden et al, 2002). Men felt there was no one they could openly communicate with about their concerns. They perceived that the shortage of staff and busy schedule contributed to this (Nanton & Dale, 2011; Harden et al., 2002). Men felt that PCa was not prioritized by healthcare and society as other cancers because of their experiences (Nanton & Dale, 2011).

With respect to treatment decision-making, men understood the importance of autonomy (Sattar et al., 2018) but reported that GPs failed to communicate sufficient information. And most times, men described information were outdated and contradictory (O’Callaghan et al., 2014; Sinfield et al., 2008). This differed between oncologists and GPs, causing distress in choosing treatment (Boehmer & Clarke, 2001a). Those that received information reported feeling relieved of concerns. However, some men that desired to ask questions failed to do so because they perceived it was the doctor’s duty to provide information (Mathers et al., 2011). With regards to the biopsy procedure, most men felt unprepared due to not being told of what they were having. For example, a man stated his doctor did not tell him the name of the procedure but told him it would alleviate pressure and pain (Walsh & Hegarty, 2010).

In relation to treatment, some men felt forced towards decision making, due to bias statements (O’Callaghan et al., 2014), and some felt unable to ask questions because they lacked knowledge (Sinfield et al., 2008). Men felt unprepared prior to and post treatment due to lack of information (Gray et al., 2000a, Harden et al., 2002, Fitch et al., 1999), which led to distress and pending uncertainty. Men and their partners felt disregarded by healthcare providers when partners were not invited or encouraged to attend consultations; not allowed to ask questions and follow up support was not provided (Sinfield et al., 2008). Patients felt that little time (Lehto et al., 2015) and attention was paid to their concerns (Sinfield et al., 2008). This was also reported among couples that felt that no attention was given to how they were coping with sexual dysfunction (Milne et al., 2008). Whilst spirituality helped the majority of men to cope during the trajectory of care for PCa (Anderson et al., 2013; Jonsson et al., 2010; Ng et al., 2006), there was only one study in which men felt talking to God would contribute to ‘low spirits’ (Ervik & Asplund, 2012).
2.2.29 Conclusion

The review of relevant literature on men and partners’ experiences of PCa revealed a dearth of studies that examine their beliefs in context of their PCa experiences and factors that impinge of these in relation to ethnicity and help-seeking. BME groups of men along routes to diagnosis were poorly represented. This identifies gaps that address how men’s beliefs and culture affect their experiences during diagnosis and treatment; and the impact on masculinity on these. These align with the findings of the SR, which highlighted a dearth of beliefs that specifically relates to men’s interpretation of symptoms and help-seeking actions. This literature review further examined men and partners experiences of PCa along routes to diagnosis, looking at aspects of diagnosis and treatment and how these impact on their beliefs. This highlights a poor representation of BME men’s PCa experiences and how their experiences impact on masculinity, their lay beliefs and culture and symptoms. The theoretical literature is examined next.

2.3 Part Three: Review of Theoretical Literature

2.3.1 Introduction

The first two parts of the literature review highlights significant gaps of men and partners’ experiences of PCa. The SR examined beliefs regarding men’s interpretation of symptoms and help-seeking behaviours, whilst the review of studies examining their experiences along routes to diagnosis reveals a lack of knowledge of PCa and links with masculinity and beliefs along these care pathways for this disease. The last part of the literature reviewed the empirical studies in relation to men’s cultural beliefs about changes to their bodies and symptoms that influenced help-seeking actions. The review highlighted a dearth of studies with these research foci and underscored a need for further empirical research in relation to lay beliefs, culture and symptoms, and masculinity as it pertains to men with PCa (King-Okoye et al., 2017).

This part of the chapter explores further the theoretical basis for understanding lay beliefs, culture and symptoms and masculinity and sets out the theoretical frameworks upon which this research study is based. It draws upon a wide range of theoretical frameworks, as the phenomena being examined overlaps with different disciplines. As such, I first discuss disrupted biography and illness experience in relation to Bury’s (1982) biographical framework and Radley’s (1994) illness
I then explore masculinity as theorized by two widely utilised frameworks: Connell (1987; 2005) and Kelly (2004). I provide a summary of these concepts and highlight gaps in the identified theoretical frameworks and the PCa literature and how this guided the aims, objectives and research questions for this study.

2.3.2 Bury’s conceptual framework of biographical disruption

As a sociologist, Bury’s original intent was to critically explore personal experience and social structure through his research (Collyer, 2015). Bury (1991) defines an illness experience as meanings people ascribe to changes in their bodies, encompassing actions utilised to mitigate and manage symptoms and adapt to these. Bury (1982) presents a conceptual framework of biographical disruption to explain the concept of the illness experience from a reactive perspective (Farrimond et al., 2010; Radley, 1994).

2.3.3 Context in which Bury’s framework originated

Bury’s (1982) framework was based on explorative research conducted among people (n=30) who experienced symptoms of rheumatoid arthritis and was subsequently diagnosed. This consisted of 25 women and five men from a working-class social background. Bury found that the diagnosis of rheumatoid arthritis caused a major disruption in structures of everyday life, which triggered a “rethinking of the person’s biography and self-concept” (1982, p. 169) and strategies employed to “normalize in the face of disruption” (1982, p. 177).

2.3.4 Features of Bury’s biographical disruption

Three features of biographical disruption are described within Bury’s conceptual framework that focuses on introspective reasoning as a key concept underlying these. The first feature of disruption occurs towards assumptions and behaviours at the onset of symptoms. This triggers introspective reasoning as to, ‘what is going on here’ (Bury, 1991, p. 455) regarding bodily changes that were not brought into consciousness until that point in time. Common sense seeks to understand, interpret and respond to changes in the body (Bury, 1991). As such lay perceptions come into play to make sense of the experience, which usually occurs within the context of the immediate external environment and culture. As changes in the body progress, a biographical shift from perceptions of normal bodily representation.
functioning to abnormality may occur, which influences individuals to hide or disguise symptoms during this time. The emerging illness also triggers anxiety, disbelief and uncertainty in recognising bodily changes as an illness (Bury, 1982). This links with Anderson’s model whereby individuals’ perceptions of bodily changes influence self-appraisal of symptoms (Andersen et al., 1995; Walter et al., 2012).

The second feature of disruption occurs as changes in the body progresses and uncertainty ensues in response to the ‘impact and course of the condition and appropriate behaviour to adopt’ (Bury, 1991, p. 172). This triggers introspective reasoning as to, ‘why me’ and ‘why now’. Individuals may cope with the illness experience by legitimising changes within their bodies to that of their lay analysis of the experience, which usually occurs in the absence of medical knowledge (Bury, 1991). Viewing the illness as an external force may influence individuals to adopt a victim-oriented approach to the illness experience as the effects invade their day-to-day activities (Bury, 1982). Apart from bodily changes, the impact of the illness also triggers questioning of certain aspects of identity such as social roles (Bury, 1982). Bury’s biographical disruption has been supported by other chronic illness studies in relation to effects on identity and self-concept. For example, Charmaz found that disruption from chronic diseases mainly occurred from the perspective of self-as-person and identity (Charmaz, 1983, 1994; Charmaz & Rosenfeld, 2006). Charmaz claims that access to medical knowledge enables a re-evaluation of the illness as separate from self-as-person, identity and the need for medical intervention (Charmaz, 1983; Trusson, 2013). As such the search towards a more comprehensive level of explanation causes a disruption of ‘structures of explanations’, which entails perceptions, interpretations, moral concerns and beliefs. This causes individuals to rethink their biography and self-concept in relation to the effects of the illness (Charmaz, 1983). These findings were also echoed in other types of cancer research studies, such as breast cancer in women (Fisher & O’Connor, 2012), colorectal cancer (Salamonsen et al., 2016), and PCA (Cayless et al., 2010). Anderson’s model of care also identifies how interpretations of symptoms can influence medical help-seeking. Some triggers to help-seeking were highlighted as an interpretation of symptoms as red-flags, noticeability of symptoms by others, and accessibility and availability of HCPs (Andersen et al., 1995; Scott et al., 2013).

And finally, the third feature of Bury’s conceptual framework outlines the mobilization of resources in response to the disease progression. This occurs via individuals’ introspective reasoning as symptoms become transparent and pertain mostly to the presence or absence of a supportive social network. Social network relates to friends, family and community involvement towards the recognition and
adaptation to the illness as it becomes a focal point (Williams, 2000). Disruption occurs via meanings individuals ascribe to the illness experience as significance and consequences (Bury, 1991). With regard to significance, the symbolic meanings of the illness are construed as affecting social relationships (Bury, 1991). Individuals may respond through social isolation (Strauss, 1975) due to perceptions of dependency on others, and associations of stigma from the illness leading to embarrassment and anxiety over the illness (MacDonald & Anderson, 1984). The meanings as consequences relate to the practical aspects (Rosenfeld, 2006) or resources required due to the implications of the illness experience. Factors such as financial aspects, re-orientation to work duties and management of time may have implications to help-seeking behaviours (Bury, 1982). Two studies are discussed below, which highlight their applicability to Bury’s framework of biographical disruption.

2.3.5 Bury’s framework: Extension to other conditions

This theory has since been developed and extended to cancer research (Cayless et al., 2010; Fisher & O’Connor, 2012; Hubbard et al., 2010; Salamonsen et al., 2016), motor-neurone disease (Locock et al., 2009) and other self-limiting diseases (Locock & Ziebland, 2015) other than rheumatoid arthritis to inform our understanding of biographical disruption. Bury’s framework has also been applied to victims of domestic violence (Tower et al., 2012) and bereaved families of suicide victims (Owens et al., 2008). Bury asserts that the life course of diseases or circumstances can be viewed as continuity and discontinuity (Bury, 1982). In relation to continuity, events are anchored along a biographical timeline representing the past, present and future (Corbin, 2003). The effects of the illness experience or circumstance disrupt or cause a discontinuity in events that were once viewed as normal or part of individuals’ culture (Corbin, 2003).

2.3.6 Application of Bury’s conceptual framework of biographical disruption

Bury’s framework of biographical disruption has been used by Cayless study to explore men’s experiences of PCa from a general perspective (Cayless et al., 2010), in addition to the theory of liminality (Navon & Morag, 2004). Cayless et al., (2010) interviewed men (n=10) at three points, which were considered 'critical'. These were at diagnosis, treatment and follow-up. Cayless study highlighted
how disruption may not only occur during diagnosis, as postulated by Bury (1982) but extends beyond the diagnostic period (Cayless et al., 2010). However, it can be argued that disruption also occurs prior to diagnosis due to the disrupted effects of symptoms that may be experienced by men, such as urinary changes.

Themes reflected in Cayless study were how acceptance and expectations of the diagnosis of PCa were experienced, the disruptive effects of treatment and men’s perceptions of the future (Cayless et al., 2010). Although some aspects of the supporting data were relevant to Bury’s framework, the authors indicated that participants were knowledgeable of other men diagnosed with PCa within their social network, which they believed helped them cope with their diagnosis. However, they did not indicate in what ways this was useful towards how men coped. Additionally, the excerpts demonstrated were short, ambiguous and open to multiple interpretations. For example, one man monitored his PSA because of his family history of PCa. He stated that ‘it was never a surprise’ when he was diagnosed with the disease (Cayless et al., 2010, p. 14). This could be interpreted as a non-disrupted event in that he was already prepared for a diagnosis of cancer. The supporting data excerpt did not demonstrate his perceptions of his experiences.

Furthermore, the authors in Cayless study did not state the staging of cancer for any of the participants nor indicated if they experienced any symptoms even though it was specified that men’s pre-diagnosis experiences were one of the focal points of the interview (Cayless et al., 2010). The symptom experience leading up to diagnosis is relevant to Bury’s primary feature of disruption in the initial recognition of symptoms and responses to these (Bury, 1982). This is also critical towards having an understanding of meanings and significance of the illness experience, which may differ significantly among men that were asymptomatic at the time of diagnosis. The analysis appears to be more descriptive than interpretative, and the focus was mainly directed to the effects of treatment on self. Moreover, the meaning of the experience is central to Bury’s framework of disrupted biography (Bury, 1982), which may not have been thoroughly represented in the findings of the study. However, Bury’s foci are from a sociological lens, which leaves a gap in relation to psychological and gender-lens perspectives. A psychological viewpoint may have identified men’s beliefs and perceptions of their bodily changes, appraisal and help-seeking in context of their immediate external environment. Additionally, even though one account of the disrupted effects of urinary catheterization in relation to sexuality was given (Cayless et al., 2010), Bury’s framework could not sufficiently examine the
disruptive impact on men’s masculinity, such as gender-roles, self-concept and identity and relationships inclusive of sexuality. A gender lens also has to be taken into consideration when examining men’s perceptions of illness in relation to PCa. Both masculinity and psychological factors play a critical role towards appraisal; help-seeking behaviours and men’s experiences along PCa care pathways Kelly (2009) highlights that PCa is unique to men and how masculine embodiment as it pertains to a diagnosis of PCa influences men’s health practices. He posits that men’s PCa experiences are dynamic in nature, which can change their social constructions of reality. Radley’s (1994) framework of illness representation and theories of masculinity address these gaps and are examined later on.

The perspectives of care pathways as seen through the eyes of patients (n=9) diagnosed with colorectal cancer were examined in a qualitative longitudinal study in Norway (Salamonsen et al., 2016). The researchers used Bury’s aforementioned framework to explore patients’ experiences of how their pathways were disrupted. Whilst Bury’s framework was applicable towards highlighting the disruptive effects at the point of cancer diagnosis and throughout care pathways, one key finding that was underexplored was the impact of life course disruptions prior to the illness experience and diagnosis. Salamonsen et al., (2016) highlighted these disruptions as pertaining to financial, emotional and social matters, which augmented the diagnosis experience. For example, patients in the study identified death and managing adult children with mental illness as being disruptive to their emotional wellbeing prior to their diagnosis of cancer. Whilst Bury postulates that the disease causes a discontinuity in events once viewed as normal, the ‘cultural definitions of normalcy’ (Becker, 1997 cited Salamonsen et al, (2016), p. 1597) may differ for patients as seen in this study and may occur prior to the symptom experience and diagnosis. Becker (1997) highlights the importance of cultural dynamics that underpins individuals’ lives, which may differ in relation to ethnicity, geographical location and within social structures. These findings highlight how an examination of pre-diagnosis experiences inclusive of culture is critical to grasp a holistic view of the phenomena in addition to diagnosis and post-diagnosis experiences.

Additionally, patients’ accounts of their pathways in Salamonsen study were dependent on the health of their spouses, relationships and concern for the future (Salamonsen et al., 2016). For example, Siri, a research participant was so worried over her husband’s illness and the future of her three children that she had very little time to focus on her own health needs (Salamonsen et al., 2016, p. 1596). Bury’s framework locates the impact of the illness experience in relation to the social roles of patients. He highlights that the symptoms, diagnosis and navigating resources along care pathways post-
diagnosis may affect patients’ social roles (Bury, 1982). This premise is made in context to the disease perspective. What remains deficient are how patient roles are affected not only by the disease but also in context to the subjectivity of the illness experience in relation to ill health, existing relationships, significant others’ roles and responsibilities since these are pivotal towards well-being, compliance and health needs (Radley, 1994). Hence, how patients perceive family and significant others’ roles are important to gain a comprehensive understanding of patients’ experiences.

2.3.7 Challenges of Bury’s framework of biographical disruption in the literature

This framework has been challenged on the grounds that biographical disruption implies a negative experience (Charmaz, 1983; Locock et al., 2009) and may not represent everyone’s chronic illness experiences (Pound et al., 1998; Williams, 2000). For example, Frank (1993) purports that a disruptive event may be considered life affirming; this can enable individuals to experience epiphanies or life-changing experiences. Other sociologists have challenged this assumption that biographical disruption may not necessarily be negative or positive but anticipated normal illness. This was reflected as ‘biographical flow’ (Faircloth et al., 2004, p. 356), ‘biographical continuity’ (Williams, 2000, p. 52), biographical confirmation (Williams, 2000, p. 50) and inevitable with “greater sense of acceptance” (Pound et al., 1998, p. 502).

2.3.8 Gaps in Bury’s conceptual framework of biographical disruption

Whilst Bury’s framework was based on participants’ experiences of being diagnosed with rheumatoid arthritis (Bury, 1982) and may be applicable to other diseases, it utilises a sociological lens that narrowly focuses on the social impact of the illness experience. This is in relation to the problematic or reactive issues (Radley, 1994) surrounding symptom experiences and not individuals’ responses associated with these (Bury, 1991, p. 451). This caused Bury to change his focus on problems experienced (1991) to how people use agency to respond and overcome these disruptions (2001). This shift highlighted the importance of lay beliefs and deeper cultural meanings of illness causation and responses to these (Bury, 2001).

However, what remain deficient in Bury’s framework are the psychological context of the illness experience with regard to individual experiences, within relationships and gendered dimensions. Bury
(1982; 1991) showed how an emerging illness disrupts individuals’ normal biography; however how relationships are disrupted were not sufficiently represented. With regard to the phenomena for this study, the roles of women in relation to their spouses’ PCa experience are important to unearth how they cope, adjust and support men throughout the course of the illness and along care pathways. Moreover, Bury’s framework is limited towards how masculinity is operationalised during the illness experience, such as gender-roles, sexuality, self-concept and identity. This was also reflected in the unequal gender distribution amongst study participants in his original fieldwork (25 women versus 5 men) (Bury, 1982). An alternative or complimentary framework is that of Radley’s (1994) illness representation model which emphasizes the importance of a social-psychological lens and ‘preventative model of healthcare’ (Farrimond et al., 2010; Radley, 1994) in relation to men and their partners’ experiences of PCa.

2.3.9 Radley’s framework of illness representation

As a social psychologist, Radley’s quest was to gain insight into individuals’ experiences of illness with a specific focus on how they conceptualise the body as a site of disease and preventative model of healthcare. That is how individuals adjust, cope and counter the illness experience along different stages of care pathways (Radley, 1987). In relation to the illness experience, Radley’s (1994; 2000) framework is organized around three main concepts: self and illness perceptions, the role of lay referral network and communicating illness. His framework utilizes a social-psychological lens that looks beyond the physical or reactive effects of the illness experience as seen with Bury’s biographical disruption (1982). Radley’s model identifies coping strategies individuals utilise in the face of illness and the social contexts and symbols associated with these (Radley, 1994).

2.3.10 Context in which Radley’s framework originated

Radley’s framework was centred on extensive fieldwork conducted among patients (n=40) with coronary heart disease who were awaiting bypass surgical graft procedures (CABGS) and those (n=40) that received CABGS. He specifically examined men and partners’ beliefs and expectations of the illness and surgery, styles of adjustment to the illness and the procedure, their roles and position in the home, patterns of activities and coping. He found that styles of adjustment differed among groups that were awaiting surgery compared to those in recovery (Radley & Green, 1985).
2.3.11 Features of Radley’s illness representation framework

Radley purports that individuals socially and culturally construct the illness experience, which influences their beliefs, perceptions and reactions to bodily changes and in turn social interactions (Radley, 1994). He asserts that underlying factors such as the severity of symptoms and perceptions of the illness experience impact individuals’ construction of the illness in relation to control (Radley, 1994). For example, Radley claims that people ignore symptoms when their perceptions of the illness are trivial or temporary. This usually occurs when symptoms are assessed as not interfering in their day-to-day activities and are deemed to be under control. However, individuals are more inclined to seek medical help if they perceive that these changes are serious or severe or not within their control (Radley, 2000).

Radley (2000) describes how individuals’ reactions occur because of the illness experience. Mobilization of medical treatment causes major disruption, which displaces their culture that consists of the familiar self and the familiar world around them. Radley refers to this disruption as ‘a tear in the fabric of one’s life that can suddenly bring into question all the assumptions upon which it is based’ (Radley, 1994, p. 145). Individuals’ main goal is to bring restoration of purpose and meaning, control and create a sense of harmony with body, self and their environment (Radley, 1994; Williams, 1984). He asserts that individuals first consult within their immediate environment, or lay referral network to help them make meaning of their bodily changes, and sanction whether medical help-seeking is warranted (Radley, 1994). The lay referral network mainly comprises of friends and family (Radley, 1994; 2000). Worsening bodily changes usually causes individuals to revise their stance on help-seeking actions. If interpretations warrant seeing a doctor, medical help-seeking is pursued. Radley (1989) also highlights how individuals’ roles and position within families may also be affected by the illness experience. This may relate to readjustments of role settings among couples. Radley (1989) also highlights the importance of marital discourse in context to class and occupation. He purports that these may influence resistance to or acceptance of health changes.

The ‘medical talk’ or the communication between doctors and patients may be challenging in light of patients’ narratives of their illness experiences and medical terminology utilised in conversations through ‘act of asking’. An accurate representation of patients’ accounts is crucial towards diagnosis and treatment (Radley, 1994). However, Radley also brings to light communicating illness as it relates to the aesthetics of illness in terms of symbolic meanings and social practices (Bury, 1991; Radley, 1989, 1999). This refers to how people actively counter, respond to and communicate features of the illness with regard to class and culture (Radley, 1989). He identifies self as complementary or opposed
to the illness experience. These reflect how individuals can positively or negatively cope and adjust to illness in light of their roles and involvement with social life (Radley, 1994).

### 2.3.12 Extension of Radley’s framework to other conditions

Apart from coronary heart disease, Radley’s (1989; 1994; 2000) framework of illness representation has been extended to other conditions such as cancer research and chronic diseases. These focus on illness narratives to understand how individuals cope during the illness experience. I now discuss two studies that are applicable to Radley’s framework.

### 2.3.13 Application of Radley’s framework of illness representation

The concept of coping and support during the illness experience was examined in Gray et al., (2000a) longitudinal qualitative study. White men (n=34) diagnosed with PCa and their spouses in Canada were interviewed at three points: before prostatectomy surgery, 8-10 weeks and 11-13 months following prostatectomy surgery. Ages of men ranged from 50-68 and their spouses 42-72. Data were analysed using constant comparison. The core category, managing the impact of illness emerged. This described how couples utilize multiple strategies to maintain control of and prevent the cancer from disrupting their lives. This was reflected via five domains. ‘Dealing with the practicalities’ highlight couples’ experiences of the diagnosis of cancer, and how they cope with sourcing information and decision-making. ‘Stopping illness from interfering with everyday life’ reflects how couples tried to minimize the disruption of the diagnosis of PCa and treatment through non-disclosure and continuing with normal activities. ‘Keeping relationships working’ describes how couples tried to be strong for each other and work as a team whilst not allowing the illness to be the focus. ‘Managing feelings’ indicates how couples took control of emotions invoked by the illness experience such as anger, grief, fear and shock. And ‘Making sense of it all’ describes how couples made meaning of their experiences in relation to the illness, outlook on life and preparations for possible death.

Being in control of emotions during the illness experience was described in this study, relevant to Radley’s framework, it highlighted how couples coped (Gray et al., 2000a). However, some underlying perceptions related to these were not examined. For example, one woman whose husband was diagnosed with PCa stated ‘I still have fears, but I don’t vocalize those to him. But I know he has the same fears.’ (Gray et al., 2000a, p. 543). The authors did not investigate the contextual or symbolic meanings behind these fears, which could be related to many factors. Additionally, spouses’ roles
were not sufficiently examined to gain an understanding of their perceptions of these with regard to appraisal, help-seeking and along care pathways for PCa. Radley (1994) points out the significance of friends and family towards meaning of symptoms, medical help-seeking and care. An understanding of spouses’ perceptions of women’s roles towards prostate health can unearth how they can be instrumental in this area of research, since lay referral network has been shown to influence how individuals perceive and respond to symptoms and ill health (King-Okoye et al., 2017).

The significance of the lay referral network towards knowledge, awareness and perceptions of PCa from a cultural context was illuminated in Salomo’s phenomenological study (Salomo et al., 2016). The researchers interviewed African men (n=10) from four regions of Namibia between the ages of 39-95 years. The study participants were representative of high-risk ethnic groups even though the sample size was small. Four themes representing men’s experiences of the impact of the illness in the midst of a lack of knowledge and misconceptions of PCa, and experiences with families and communities, and nurses were described. Men diagnosed with PCa experienced social isolation from their spouses due to perceptions that this disease could be contracted sexually. Moreover, men felt abandoned by families and communities who stereotyped them as being homosexuals due to this diagnosis. These misconceptions resulted in men’s lack of family and community support along care pathways. Men’s perceptions of feeling isolated and abandoned also extended to nurses whom they described as uncaring, unsupportive and absent from wards (Salomo et al., 2016). There is a need for further exploration into men and their partners’ personal beliefs. For example, the factors linked to participants’ belief that PCa occurs in gay people were overlooked. This may have been associated with constructions of masculinity, culture and social norms, which will be discussed in 2.3.15.

2.3.14 Gaps in Radley’s illness representation framework

Radley’s framework provides insight into the social psychological experiences of illness as highlighted in Gray et al., (2000a) study. These are inclusive of social roles, coping, and contextual and symbolic meanings of beliefs and perceptions in relation to the illness experience (Radley, 1994; 1999). Radley’s work shifted recently to aesthetics of the illness, which was significant towards conceptualising the body as an active part of countering the illness (1999). He also highlights aspects of masculinity in relation to the illness experience such as role adjustments (Radley, 1994). However, his scope of illness representation is quite limited from a masculinity frame of reference as seen in Salomo et al., (2016) study. These have significant implications to the illness experience. Masculinity and how it impacts on men’s experiences of illness are discussed next.
2.3.15 The concept of masculinity and men’s help-seeking

An understanding of masculinity is significant to the phenomena being examined since PCa impacts men physically, socially, mentally and psychologically (Rivas et al., 2016). Furthermore, the literature review highlighted how men’s views of masculinity vary and may be related to cultural beliefs and practices. The topic of masculinity goes beyond sex, which is distinguished from gender in the field of social sciences. Whilst sex is conceptualized as biological determinants that determine whether a person is male or female, gender is related to social constructions of meanings associated with being a man or woman (Sabo & Gordon, 1995). These social constructions are displayed through appearances, behaviours and attitudes. Masculinity is defined as the essence or inner core of a man’s being, which impacts everyday actions (Connell, 1995).

2.3.15.1 Hegemonic masculinity

Hegemonic masculinity is a dominant type of masculinity that lies at the superordinate position of the stratification ladder of masculinities (Connell, 1987; Courtenay, 1999). It is considered an ideal demonstration of maleness. Hegemonic originates from hegemony, which means power and dominion (Connell, 1985). This form of masculinity supersedes other representations of masculinities such as complicit, marginalized and subordinate masculinities (Connell, 2005) and is based on specific traits that men demonstrate (Connell, 1987). Complicit masculinity describes men that do not conform to all the traits of the ideal man but still benefit from being male. Marginalized masculinity refers to men that do not have access to all the traits of hegemonic masculinity, such as being Black or ill. However, they still subscribe to these norms. And subordinate masculinity describes men that exhibit qualities or traits that oppose hegemonic masculinity, such as being effeminate or gay. The social attributes of hegemonic masculinity as postulated by social scientists have infiltrated social norms with the expectation that men are strong, powerful, self-reliant and resourceful beings (Addis & Mahalik, 2003; Connell, 2005; Courtenay, 2003). This has been described as the ‘current most honoured way of being a man’ (Connell & Messerschmidt, 2005, p. 832). Connell postulates that hegemonic masculinity resides only in highly intelligent upper class White European men (Connell, 2005). Those that fail to embody or support all the succeeding traits including men that are disabled, from a lower class, less educated, Black ethnicity or gay are positioned subordinately (Connell, 1987).
The literature highlights seven traits that define hegemonic masculinity. These are (i) power and success, (ii) self-reliance, (iii) stoicism (iv) toughness (v) heterosexism (vi) restricted expression of emotion/lack of emotional sensitivity and (vii) misogyny (Cheng 1999; Frank 1991; Kiss and Meryn 2001). The concept of hegemonic masculinity as a sense of agency is meaningful as it provides insight into the uniqueness of being male. This is relevant when exploring illness and can relate to how masculinity supports and controls the illness (PCa) experience. However, the notion that hegemonic masculinity occurs only in a predefined male population is debated in the literature (Connell, 1995; Courtenay, 2000; Hearn et al., 2012; Kimmel et al., 2005). Wall & Kristjanson (2005) postulate that masculinity should be culturally located in relation to contextual factors such as ethnicity, class, and the illness experience. This is a better approach to gaining insight into the understandings of men from differing ethnicities, nationalities and socioeconomic backgrounds (Fetterman, 2009).

However, some studies have overlooked sex as a key component of men’s masculinity. For example, Kelly (2004) argues that the illness experience challenges a man’s ability to perform physically, socially and destabilizes his identity, which are not only related to traits highlighted by Connell, but by his roles, social expectations of his roles, his self-identity and relationships. This disruption shifts his masculine image (Strauss, 1969) and impinges on his perceptions and sense of self (Kelly & Field, 1996). Kelly bases his argument on an ethnography study conducted with White (n=14) men in England. Analysis of data revealed that an intricate relationship occurs between men’s sexuality and their personal, cultural and social being. Even though the sample was not representative of varying ethnicities, which may impact men’s beliefs and experiences differently, Kelly’s work underscores the significance of man’s sexual function in context of the PCa experience. I now discuss two studies that are applicable to theories of masculinity.

2.3.16 Application of masculinity in the illness experience

Masculinity in relation to the illness experience was examined in Chapple and Ziebland (2002) study. They conducted unstructured interviews with 52 men between the ages of 52-80 that were predominantly white British men. The aim was to explore how the disease process and treatment impact perceptions of self, their bodies and roles inclusive of masculinity. Most of these men were receiving hormonal and radiation therapy. The findings reported men’s help-seeking behaviours and experiences of treatment. Some connections to masculinity were elicited such as the macho image of men, concealment of emotions described, as ‘men don’t cry’ and weakness, and worry over the impact
of the illness on their role as breadwinner of the family. This was also inclusive of sexual and physical burdens.

Although some actions linked to masculinity were evident in Chapple and Ziebland’s study, these were not considered as part of the analysis. For example, all but one of the men preferred to be interviewed by a female rather than a male researcher. Also, the research participants were not representative of other ethnic groups. However, the findings were instrumental towards demonstrating men’s embodiment of masculinity in relation to PCa for that era. These studies are quite old now and cultural views are quite dynamic and may be different in 2018 for groups of men. Also, what remains deficient is an exploration of masculinity as it relates to men’s PCa experiences among men from differing ethnicities, socioeconomic backgrounds and geographical locations.

A recent systematic review that examined Black African and Black Caribbean post-treatment experiences for PCa highlighted a dearth of research conducted among this high-risk population (Bamidele et al., 2018). Research conducted among this target group may provide insight into the influence masculinity has in a cultural context and the impact of the illness experience towards appraisal, help-seeking, diagnosis, treatment, follow-up and compliance and supportive care. This links with Bury’s framework in that he sees the symptom experience embedded within a distinct cultural paradigm, which may differ among groups of people (Bury, 1982). He also extends this to medicine, which he refers to as a cultural system (Bury, 1982, p. 179) in that it can bring healing to distressed individuals yet create uncertainty due to its limitedness. From a socio-psychological perspective, Radley (1994) associates’ culture within families that may differ with regards to their perceptions of societal roles and pressures of social norms. This emphasizes the importance of cultural context when examining men and their partners’ experiences of PCa.

Through a grounded theory and a gender lens framework, Wenger (2013) examined how men make sense of cancer, which yielded a substantive theory of ‘the assaults of cancer’. This reflects the impact of cancer as a biographical disruption on men’s help-seeking actions. Canadian men diagnosed with a range of cancers were interviewed (n=30). Four emerging themes were elicited. These were ‘a troubled future’, which described the diagnosis of cancer and fears regarding treatment and survival, ‘a discordant present’, which looked at the constraints and challenges of day-to-day functioning; uncertainty in managing disruptions on self and towards the future; and isolation, in relation to
disconnect from self and relationships. ‘Resistance to change’ and ‘recognition to change’ highlighted men’s attempt to regain control of self, amidst the illness and knowing when to seek help.

Wenger (2013) showed how men demonstrated hegemonic masculinity through stoicism, self-reliance and restricting emotions throughout their cancer journey, which can pose a threat to requesting and accepting support. Whilst this study contributed new knowledge to the field of cancer in relation to the substantive theory, only two accounts of men’s PCa experiences were noted. The PCa experience may differ significantly in comparison to other cancers. Analyses across studies showing the impact of differing cancers on men’s masculinity would have proved beneficial towards eliciting men’s perceptions of these experiences. Also, cultural contexts in which men experienced care pathways were not addressed.

2.3.17 Gaps in masculinity frameworks

Masculinity as an isolated concept is not sufficient to explore men and their partner’s experiences of PCa in depth, as seen in Chapple & Ziebland (2002) and Wenger (2013) findings. The use of a sociological and psychological lens is also critical for this study as it links to beliefs, cultural insights and other environmental factors in relation to help-seeking behaviours. In relation to PCa, there is also a dearth of theoretical and empirical literature that identifies how masculinity is experienced among men from varied ethnic groups and nationalities, such as BME groups and factors that impinge on these. Additionally, the roles of women in context of men’s masculinity remain deficient.

2.3.18 Linkages between theoretical strands of lay beliefs, culture and symptoms and masculinity.

The previous discussions highlighted the significance that each theoretical strand (lay beliefs, culture and symptoms, and masculinity) has towards a complete understanding of men and their partners’ experiences of PCa (see Figure 8). Each of these is interwoven with the other. As such the experiences of symptoms are dependent on lay beliefs (Bury, 1982), culture (Bury, 1982; Corbin, 2003; Radley, 2000) and constructions of masculinity (Kelly, 2004; 2009); whereas how masculinity is operationalised affects lay beliefs (Connell, 1987; 2005), roles and identity (Kelly, 2004). And the experiences of symptoms affect individuals’ self-concept and identity (Bury, 1982; Charmaz, 1983). Culture impacts the experience of symptoms (Bury, 1982; Radley, 2000) and the embodiment of
masculinity are dependent on belief-systems and the presentation of symptoms (Kelly, 2004; 2009). The interrelationships between these theoretical strands are significant to gaining a holistic understanding of the phenomena.

![Figure 8. A representation of the three theoretical strands that form the theoretical framework for this study.](image)

2.4 Summary of findings and gaps in the literature

The theoretical and empirical concepts highlighted in this chapter show a dearth of research that examines men and their partners’ beliefs and perceptions of their PCa experiences from a personal, cultural and collective context. Additionally, there is a paucity of research that demonstrates how masculinity and other factors impinge on men and their partners’ reasoning, attitudes and judgements as it relates to appraisal of symptoms, help-seeking and aspects of care along the PCa diagnosis pathway. In relation to the country and population to be investigated of TT, there is no study that has examined these phenomena in light of the high-risk ethnic groups and the steadily increasing PCa incidence and mortality rates (Hosein et al., 2016). Women’s role in relation to early PCa detection could be valuable in help-seeking, promoting an earlier diagnosis, and these topics remain under researched. It is critical that women’s role be investigated considering that they too share the journey with their partners.
2.5 Research Aims and Objectives

In light of these gaps in understanding of PCa routes to diagnosis and the sociology and psychology literature in informing public health there is a need for research. The aim of this study is to investigate beliefs and meanings to diagnosis and treatment of men newly diagnosed with PCa; and the role and impact their partners play in cancer detection in TT. This research study will aim to identify and contextualise issues faced by men newly diagnosed with PCa and their partners in order to develop a substantive grounded theory that best support public health messages.

2.6 Research Questions

My research questions are as follows:

2.6.1 What are newly diagnosed men’s beliefs, about their illness, during their journey to diagnosis and treatment of PCa in TT?

The main aim of this research is to explore men’s (diagnosed with PCa) beliefs and meanings along their trajectory of care for PCa in TT. The aforementioned theoretical frameworks show that beliefs form part of culture, masculinity and experiences of health and illness. Bury’s (1982) view of illness as a biographical disruption will be invoked in order to examine how men experience PCa. However, the study will not only focus on the emerging illness as Bury did, but will also explore men’s pre-diagnosis, diagnosis and post-diagnosis experiences. This would allow a better perspective of men’s beliefs and meanings throughout their trajectory of care. Additionally, a bi-focal examination from the perspectives of masculinity and illness theoretical lens will be considered. I am also expanding on Ocho and Green’s (2013), study which is the most recent known to be conducted in TT about men’s perceptions of PCa in context of screening. Ocho and Green (2013) conducted 14 focus groups with men between ages 19-60. They found that the major barriers to accessing health services in relation to PCa screening were cultural beliefs. However, men interviewed were not diagnosed with PCa. The current study includes the narratives of men diagnosed with PCa along routes to diagnosis, which also includes PCa screening as well as pre-diagnosis, diagnosis and post-diagnosis and treatment experiences. The study also reflects a wide range of men’s ages, including the 60+ age group that has the highest incidence of PCa.
2.6.2 What are partners beliefs of their spouses, newly diagnosed, illness during their journey to diagnosis and treatment of PCa in TT?

This underlying question aims to explore partners’ beliefs and meanings with regard to men’s experiences. Radley’s (1994) illness representations highlight the importance of family members, especially the roles of spouses with reference to the illness experience. The significance of men and their partners and the impact of ethnicity were highlighted in Rivas systematic meta synthesis of qualitative studies (Rivas et al., 2016). No study known to the author has explored partners’ beliefs and experiences of their spouses’ PCa journey in TT. This study aims to capture these in order to reveal women’s roles and important factors that impinge on men’s presentation of symptoms, access to health services and diagnosis and treatment of PCa in TT.

2.6.3 Why do men access healthcare services late in TT?

This question unearths barriers to prostate care for men in TT. This links to Andersen’s model of care in identifying men’s experiences of appraisal and help-seeking as it relates to processes, intervals and contributing factors (Walter et al., 2012). However, these are looked at from broader perspectives and not confined to the boundaries of processes identified in Andersen’s model. I am also examining TT men’s access to healthcare in context of the findings of the recent systematic review (King-Okoye et al., 2017). This will help to better understand how TT men interpret their symptoms experienced and make decisions on their need to seek medical help.

2.6.4 What are the differences between the experiences of men and their partners in the two islands of TT?

It is important to gain insight into men and partners’ experiences of PCa in both islands of TT. This question will enable a comparative view of men and partners’ beliefs. Patrick (2015; 2016) highlighted screening studies conducted in Tobago; whereas Trinidad has no ongoing PCa screening programmes (Persuad et al., 2018). As highlighted in the introduction, TT is a multi-ethnic, multi-cultural and multi-religious nation. Beliefs may differ among the diverse population, which may influence experiences along routes to diagnosis for PCa. There are also variations in access to oncological services between the two islands as the Tobago oncology unit was recently established and provides limited diagnostic treatment services with one shared consultant. Whereas, well-established main oncology centres, such as the National Radiotherapy Centre are located in urban areas within Trinidad. Having a
comparative understanding of men’s beliefs and experiences within both islands will decipher how facilitators and barriers to prostate health services vary for TT.

2.6.5 To develop an explanatory theory representative of the experiences of men newly diagnosed with PCa and their partners during their journey to diagnosis and treatment of PCa in TT

It is critical to generate a substantive theory from data collected that represents the experiences of participants (men and partners) along routes to diagnosis for PCa in TT. This will be useful towards the objective of the study in identifying the social processes and actions surrounding men’s late presentation, help-seeking delays, delayed access to health services and delayed presentation and diagnosis of PCa.

The research paradigms, methodology, methods and design utilised for this study are discussed in the following chapters.
CHAPTER THREE - RESEARCH PARADIGMS AND RESEARCH METHODOLOGY

3.1 Introduction

This chapter presents a critical discussion and justification for the research paradigm and research methodology for the study and is divided into two sections. In the first section I discuss common research paradigms and highlight why interpretivism was selected for the study. In the second section I reflect on my decision to use Straussian GT as most appropriate to answering the aims and objectives of the study.

3.2 Research paradigms: Overview

In this section I give an overview of research paradigms and the one that was generated from the study aims and objectives. The primary aim of any scientific research is to acquire knowledge through empirical evidence (Strauss & Corbin, 1998). A research paradigm guides the researcher to achieve this (Guba, 1990). The term paradigm is derived from the Greek word “parádeigma” which means pattern, example or sample (Liddell et al., 2002). The use of paradigms started with Thomas Kuhn, an American physicist, historian and philosopher of science. He described ‘paradigm’ in his book, ‘The Structure of Scientific Revolutions’ as providing a framework and justification for academic performance (Kuhn, 1962). In relation to social research, a paradigm is defined as ‘a shared worldview that represents the beliefs and values in a discipline that guides how problems are solved” (Schwandt, 2001 p.183-184). The word paradigm has been used interchangeably with broad perspectives of research methodologies (Neuman, 2000), theoretical approaches (Crotty, 1998), knowledge claims (Creswell, 2009), philosophical assumptions, epistemologies and ontologies (Crotty, 1998).

Crotty (1998) describes each paradigm as an inter-related social research process comprising of a chain with these components: ontology, epistemology, theoretical perspective, methodology and methods. She asserts that ontology and epistemology are philosophical assumptions or the core principles that undergird each research paradigm (Crotty, 1998). Ontology is derived from two Greek words: ‘on’ which means ‘being’, and ‘logia’ which means ‘study’ (Liddell et al., 2002). It is defined as
‘a study of being’ (Blaikie, 2010) and is ‘the branch of philosophy or metaphysics concerned with the nature of existence’ (Abercrombie et al., 2006). It concerns how reality is constructed (Denzin & Lincoln, 1998; 2000), whether in a subjective or objective manner (Crotty, 1998). Epistemology is derived from the Greek word, ‘epistēmē’, meaning ‘knowledge’ and λόγος, ‘logos’, meaning “logical discourse” (Liddell et al., 2002). Epistemology concerns the very basis of how we obtain knowledge, as to ‘how we know what we know’ (Crotty, 1998 p. 8). It explores the relationship between the knower and the known (Guba & Lincoln, 1989). There are a number of paradigms and these continue to evolve. However, I will focus on two common research paradigms in the following section.

3.2.1 Common research paradigms: positivism, interpretivism

Two common research paradigms discussed here are positivism and interpretivism.

3.2.1.1 Positivism

Positivism or empiricism is deeply rooted in natural sciences and mathematics (Thompson, 1995). For this reason, positivism is considered an ‘allegiance to the methods of natural sciences’ (Cohen et al., 2011, p. 7). It emerged from the philosophical ideas of a French philosopher; August Comte who purported that human behaviour can be explained through a rigorous process of scientific inquiry (Crotty, 1998). The positivist ontology is that of realism, which claims that a single reality exists that can be observed and measured through hypothesis testing, causal relationships, and validation (Guba & Lincoln, 2008; Macionis & Gerber, 2010). The epistemological position is that of objectivism, which holds that meanings reside in objects and not conscience. Positivists look for objective causes of human behaviour (Thompson, 1995). As such they believe that knowledge should remain uncontaminated and without researcher bias. Positivists claim that the researcher remains independent, ‘value-free’ and separate from what is being researched so as to maintain objectivity (Guba & Lincoln, 2008). Positivists assert that the laws that govern reality can be described, predicted and controlled. As such knowledge gained from a positivist approach is mainly through direct observations and measurements of reality (Macionis & Gerber, 2010).

The methodological approach for positivism lies in deductive reasoning, which is mainly achieved through empiricism. Studies utilising positivism adopt a quantitative style of inquiry (Crowther & Lancaster, 2008). As the focus of positivism is on valid and reliable tools to measure phenomena,
methodology utilised for this paradigm are usually experimental and survey research. Positivists observe for trends, patterns and correlations between variables (Guba & Lincoln, 2009). Whilst positivism has been viewed as trustworthy due to its objectivity, reliability and validity (Carson et al, 2001), this type of paradigm has been criticised for its deficiency towards a comprehensive understanding of phenomena (Gray et al., 2009). Positivism disregards the subjective realm of the phenomena that are beliefs, values, and experiences underlying human behaviour. Hence, this limits a holistic understanding of context and richness of individuals and environments (Gray et al., 2009).

3.2.1.2 Interpretivism

Also known as anti-positivism and negativism, this paradigm rejects positivism as it takes into account ideologies, and social, historical and cultural contexts (Cohen et al., 2007). Interpretivism has been used in a number of disciplines, including sociology, psychology and education (Willig, 2013). Max Weber is credited for its development due to his concept of ‘verstehen’ meaning, “understanding something in its context” (Holloway, 1997, p. 2). Interpretivism claims that social phenomena cannot be appropriately examined through a positivist approach. This paradigm portrays an ontological stance that there are multiple truths or realities that are socially constructed. In terms of epistemology, interpretivism is based on subjectivism (Creswell, 2003). This claims that social phenomena are subject to the actions and perceptions of social actors, in that interaction between both participant and researcher are central to this (Elster, 2007). Unlike positivism, this paradigm claims that the researcher’s role as a tool in the research process is critical. This pertains to the researcher’s values and beliefs, which Interpretivists posit cannot be entirely removed from any inquiry (Creswell, 2003).

The methodological approach for interpretivism lies in inductive reasoning, which is mainly achieved through naturalistic studies. Studies utilising interpretivism adopt a qualitative style of inquiry. Interpretivists aim for research to be participant-led (Willig, 2013). They do so through participants sharing their story and explaining their own behaviours, to unpack feelings, emotions and meanings (Cohen et al., 2007). An understanding of subjective meanings attached to observations and rich data enables the context of social phenomena to be thoroughly studied by the researcher (Creswell, 2003). Whilst this type of paradigm has been applauded for unearthing cultural beliefs, meanings underlying value-systems and multiple realities of phenomena (Denzin & Lincoln, 2011), interpretivism has been criticised for bias based on the subjective views of the researcher and a lack of generalization (Creswell, 2009). As such, positivists argue that trustworthiness of qualitative findings (discussed further in 3.16) may not be established (Myers, 2008). Methodological approaches that follow this
paradigm include SI, phenomenology, ethnography and grounded theory (Gray et al., 2009). These are further discussed in 3.3.1.1 and 3.3.1.2.

3.2.2 Research paradigm generated from study aims and objectives

The primary aim of this research study was to investigate beliefs and meanings to diagnosis and treatment of men newly diagnosed with PCa; and the role and impact their partners play towards cancer detection in TT. The objective of this research study was to contextualise issues faced by men newly diagnosed with PCa and their partners on their routes to diagnosis and treatment in order to develop a substantive theory that best support public health messages. As little is known about these phenomena, it is important that multiple truths and realities are explored along a path of discovery (Denzin & Lincoln, 2018). Beliefs align with an epistemology-ontology position that there are multiple truths and realities (Pecorino, 2000).

Beliefs can be socially constructed in relation to environment, culture and the illness experience (Bury, 1991). As positivism is based on a single reality and neglects subjectivity (Guba & Lincoln, 2008), it is not suitable to gain an in depth understanding of the phenomena I am interested in. Gaining insight into the experiences of men and their partners requires an examination of social context and processes that impact on their experiences. The role of the researcher towards interpreting meanings behind beliefs and actions is critical to the phenomena being investigated. Additionally, the interdependent relationship between participant and researcher has to be taken into consideration (Cohen et al., 2007). Crotty (1998, p. 14) posits “the distinction between quantitative and qualitative research occurs at the level of methods and not at the level of epistemology.

The paradigm of interpretivism best suits the aims and objectives of this study. It enables beliefs and meanings from the perspective of multiple realities to be unfolded and interpreted through interactions with participants and the researcher (Cohen et al., 2007). Thus, the researcher as an interpretivist seeks to ‘step in the shoes’ (Willig, 2013, p. 71) of participants to gain an understanding of men and their partners’ experiences to unravel their subjective worldview (Gupta & Awasthy, 2015). Interpretivism focus primarily on understanding and accounting for the meaning of human experiences and is based on an epistemological stance building on known beliefs (Fossey, 2002), which is applicable to the study aims and objectives. It also facilitates the development of a substantive theory in relation to men and partners’ accounts of phenomena as seen through the eyes of the
researcher (Corbin & Strauss, 2015). Table 11 summarizes my reflexivity of choosing the paradigm of interpretivism.

Table 11. The reflexivity of choosing the paradigm of interpretivism.

<table>
<thead>
<tr>
<th>Research aims</th>
<th>Positivism (Guba &amp; Lincoln, 2008; Gray et al., 2009)</th>
<th>Interpretivism (Cohen et al., 2007; Creswell, 2014)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Beliefs and perceptions</td>
<td>Single reality Unsuitable to examine beliefs and perceptions</td>
<td>Multiple realities Suitable to examine beliefs and perceptions</td>
</tr>
<tr>
<td>Meanings</td>
<td>Objectivism Not ideal to examine conscience and subjective meanings</td>
<td>Subjectivism Ideal for uncovering conscience and meanings</td>
</tr>
<tr>
<td>Experiences</td>
<td>Deductive reasoning Limited towards drawing inferences for these phenomena</td>
<td>Inductive reasoning Appropriate for looking for patterns and observations to account for experiences through theory development</td>
</tr>
<tr>
<td>Role of the researcher</td>
<td>Researcher independent/neutral Limits the researcher’s role towards data collection</td>
<td>Researcher interdependent Explores the researcher’s role in light of the phenomena</td>
</tr>
</tbody>
</table>
3.3 Why GT?

The previous section presented the justifications for using the paradigm of interpretivism as guided by the aims and objectives of the study. This section discusses why GT was selected as the primary methodology among others that are guided by the paradigm of interpretivism. SI is discussed in 3.5.1.

3.3.1 An overview of phenomenology, ethnography and grounded theory

Phenomenology, ethnography and GT are three common methodologies that follow the ontology and epistemology positions of interpretivism (Littlejohn & Foss, 2009). These three methodologies enable real life experiences to be explored and require a high degree of interaction between the researcher and research participants (Myers, 2008). I will now provide an overview of these three methodologies separately and show why GT was selected.

3.3.1.1 Phenomenology

Phenomenology originated in European philosophy (van Manen, 2016). It is derived from the Greek word “phainómenon”, which means, "that which appears" and "logos", meaning, "study" (Liddell et al., 2002). It is the philosophical study of the content of consciousness and structures of our experiences (Willig, 2013). There are three main types of phenomenology: descriptive (Husserl) (Giorgi & Giorgi, 2003), interpretive (Heidegger) (Van Manen, 2016), and interpretative phenomenological analysis (IPA) (Smith, 2011). Descriptive phenomenology also known as “positivistic’ or ‘transcendental’ describes phenomena by bracketing the researcher’s views or biases from that of the study participants (Dahlberg, 2006). This type of phenomenology posits that ‘description is primary, and that interpretation is a special type of description’ (Giorgi & Giorgi, 2008, p. 167). Interpretive phenomenology is based on the premise that all description constitutes a form of interpretation (Van Manen, 1990). Hence, this type of phenomenology integrates both the descriptions and interpretations of phenomena and ignores bracketing (Van Manen, 1990). It examines the textual accounts of those who have lived through experiences of the phenomena including the biases of the researcher (Pernecky & Jamal, 2010). Whereas IPA originates in psychology and takes an idiographic approach, which is derived from the Greek word “idio” meaning ‘one’s own’ and “graphein” meaning ‘to write’ (Bruce & Yearly, 2006). Smith et al. (2009) describes this type of methodology as ‘trying to
make sense of the participant trying to make sense of what is happening to them’ (p. 3). This involves intensive engagement within and across participants’ texts.

Even though the phenomena under examination of the current study are similar to the aim of phenomenology, that is, towards understanding the experiences of participants who have been diagnosed and treated for PCa including their spouses, this methodology was rejected for three reasons. Firstly, the intent of the researcher for this study was to identify, examine and explicate contextualised social processes that account for the phenomena (Willig, 2013). Phenomenology does not examine social processes but looks at the nature or essence of the phenomena through descriptions, interpretations and intense engagement with data (Willig, 2013). Secondly, due to the phenomena being examined, it was important to compare and analyse data from many sources that can enable a holistic understanding of the social processes involved. This includes texts, observations, research diaries, past literature and research. Whilst phenomenology may incorporate a research diary to facilitate bracketing of researchers’ views (Wall et al., 2004), it limits data collection to interviews. As such, it does not incorporate other sources of data as part of the analysis unlike other methodologies within the interpretivism paradigm (Todress & Holloway, 2010). And thirdly, one of the aims of the study was towards theory development that provides representations of participants’ experiences. Whilst phenomenology enables the researcher to gain insight into participants’ world, theory generation is not one of its outcomes (Todress & Holloway, 2010). For these reasons’ phenomenology was deemed unsuitable for the current study.

3.3.1.2 Ethnography

Ethnography originated in the field of anthropology (Mackenzie, 1994). It is derived from the Greek word, ἔθνος (ethnos), meaning “a people, nation” and ‘graphy’, meaning "field of study" (Liddell et al., 2002). It is “a particular method or sets that involves the ethnographer participating overtly or covertly in people’s lives for an extending period of time, watching what happens, listening to what is said, asking questions” (Hammersley & Atkinson, 2007, p.3).

Ethnography is often associated with SI due to its examination of culture, and relationships between culture and behaviour (Gray, 2014). From a cultural perspective, ethnography aims to observe how individuals experience phenomena to gain an understanding of social conditions, values, attitudes, behaviours, roles and interpersonal relationships and beliefs, and impact on these. Observations of actions and interactions from cultural perspectives among people (field-oriented activities) are key
features of ethnography (Lambert et al., 2011). The current study proposed to examine participants’ beliefs along PCa care pathways, which may be relevant to ethnography as a methodology.

However, ethnography was rejected for two reasons. Firstly, based on the research aims and objectives, it is important to understand the meaning of social processes as experienced by participants. Ethnography focuses mainly on descriptions of cultural perspectives of the phenomena (Lambert et al., 2011), and employs a static approach to data collection (Corbin & Strauss, 2015). From this viewpoint ethnography was not suitable, as a holistic understanding of the phenomena and the dynamics occurring inclusive of culture are the overall goals of the research study. Secondly, the main objective for the current study was to develop a substantive theory that best support public health messages. Ethnography is dependent on sourcing an existing theory that explains the data collected, and cannot foster theory development (Emerson et al., 2011; Hammersley, 1989). For these reasons, ethnography was regarded as unsuitable for the current study. Table 12 on the following page shows a summary of my research audit trail in choosing GT methodology.
<table>
<thead>
<tr>
<th>Research aims</th>
<th>Phenomenology (Giorgi &amp; Giorgi, 2008; van Manen, 2016; Willig, 2013)</th>
<th>Ethnography (Emerson et al., 2011; Gray et al., 2009; Lambert et al., 2011)</th>
<th>GT (Corbin &amp; Strauss, 2008; 2015)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Examine social processes</td>
<td>Looks at the nature or essence of phenomena through description, interpretations, intense engagement with data</td>
<td>Focuses mainly on descriptions of cultural perspectives</td>
<td>Examines social processes</td>
</tr>
<tr>
<td>Use of multiple sources of data</td>
<td>Limits data source to mainly interviews</td>
<td>Not ideal as other sources of data are needed to examine social processes in detail</td>
<td>Ideal for data collection</td>
</tr>
<tr>
<td>Development of a theory to represent participants’ experiences</td>
<td>Gain insight into participant’s worldview</td>
<td>Sources an existing theory to explain phenomena</td>
<td>Cannot foster theory development</td>
</tr>
</tbody>
</table>

Table 12: Summary of the research audit trail: choosing GT methodology.
3.4. Grounded theory methodology (GT)

GT originated in sociology and has been utilised in many fields, including nursing and health sciences (Corbin & Strauss, 2015). It has been abbreviated as GT by Glaser (discussed later on) and will be referred to as GT throughout the thesis (Glaser & Holton, 2004). It is mainly employed when examining social processes, known as the “six Cs”: causes, contexts, contingencies, consequences, covariances and conditions (Strauss & Corbin, 1998). The overall aim of Grounded theorists is to examine social structures and processes and look at how these influence events through a given set of social interactions (Corbin & Strauss, 2008), and is applicable to the aims and objectives of the current study. Why men in TT present late with bodily changes suggestive of PCa, such as blood in the urine and severe back pain remain deficient in the literature. The goal of GT will allow social circumstances of the interactions, behaviours and experiences of men and their partners’, engagement with social contacts, providers, and health systems along care pathways to be unfolded. The use of data sources such as observations, interviews and memos capture a holistic understanding of how participants define reality inclusive of culture (Corbin & Strauss, 2008). Table 12 shows a summary of the audit trail of choosing the GT.

3.4.1 Definitions

GT is defined as ‘a systematic, qualitative procedure used to generate a theory that explains, at a broad conceptual level, a process, an action, or an interaction about a substantive topic’ (Creswell, 2012, p. 423). This achieves the objectives of the study. GT utilizes specific procedures such as theoretical sampling, memo writing, constant comparison, theoretical saturation and structured coding and is rooted in symbolic interactionism (Corbin & Strauss, 2015) (discussed fully in 3.5.3). This methodology moves beyond a description of events that occur to an understanding of underlying processes, relationships, actions and interactions. It requires theoretical sampling in relation to the phenomena being investigated that is the data collected informs the data to be collected (Corbin & Strauss, 2015). Hence recruiting men and partners with differing experiences, and understandings of the phenomena will facilitate multiple perspectives of the social processes under study.
3.4.2 Controversies of GT as a method and methodology

There are controversies in the literature regarding GT’s use as a qualitative research method (Glaser, 2001), a research methodology (Glaser, 2001; Corbin & Strauss, 2015); and its application: abbreviated versus full versions (Willig, 2013). Even though the wider literature views GT as a qualitative methodology, Glaser (2001) argues that GT is a general research method and not confined to qualitative research. GT has been utilised solely as a qualitative research method to analyse data for codes, concepts and categories’ generation using its key principles of coding and constant comparison (discussed further in 3.5.3); without theory development. However, the main outcome of GT is towards theory development (Corbin & Strauss, 2015) (see 3.4.5.3). The abbreviated version of GT analyses previously collected data using GT as a research method. In this version, researchers are unable to return to the field. As such, theoretical sampling, theoretical sensitivity and negative case analysis are restricted to the texts that are being analysed. This limits the developing theory since the original data guides prospective data collection, which enables conceptual density and integration (Willig, 2013). The full GT version enables the researcher to collect and analyse data and then return to the field to collect more data. In essence, the research is guided and driven by the data collected (Willig, 2013). This research utilised the full version of GT as a research methodology, following its key principles towards a developing theory. This is discussed next.

3.4.3 Theory development

GT can produce either a substantive, middle range or formal theory (Glaser & Strauss, 1967; 2007; Polit & Beck, 2008). These forms differ due to their level of generality and level of conceptual abstraction. A substantive theory has a low level of conceptual abstraction and generality (Glaser, 2007; Polit & Beck, 2008) and focuses on a specific “substantive or empirical area of sociological inquiry” such as patient care (Glaser & Strauss, 1967, p. 32). Comparative analysis occurs between or among groups within the same substantive area. It is usually constructed through identifying similarities and differences and patterns across and within cases focussed on a similar theme (Glaser & Strauss, 1967). A middle-range theory “provides substantive structures and foundations that may facilitate the ability to observe, test and interpret phenomena so that a higher level of evidence-based research can be translated into practice” (Warren, 2016, p. 9). However, a formal theory has a high level of conceptual abstraction and generality (Glaser & Strauss, 1967) and usually begins from a substantive or middle range theory derived from previous studies. It is usually developed for a “formal
or conceptual area of inquiry” (Glaser & Strauss, 1967, p. 33). It is defined as “a theory of a substantive grounded theory core category’s general implications” (Glaser, 2011, p. 4). As such comparative analysis occurs with two or more substantive areas, since the focus is not on a single substantive case, but on how the core category relates in a broader perspective to other data and studies in the same substantive area (Glaser, 2011).

I aim to develop a substantive theory based on participants’ accounts of their experiences. In order for information to be unearthed, there must be interactions between participants and the researcher, as theory is grounded in data and must be generated from the data. In other words, this theory cannot be predetermined but can only be elicited from the data. The role of the researcher is paramount towards how the research participants construct and reconstructs reality. GT best fit the aims and objectives of this research study.

3.4.4 History of GT

Known as the founding fathers of GT, sociologists, Barney G. Glaser and Anselm L. Strauss developed this methodology during the 1960’s, when they conducted studies related to dying and chronic illness (Patton, 1990; 2002). This methodology was developed as a response to positivism and a dominance of quantitative methods in social sciences research (Denzin & Lincoln, 2005; Seale, 2002). It was observed that there was a lack of systematic guidelines in qualitative research, which prompted Glaser and Strauss to develop a method of theory generation (Walker & Myrick, 2006), rather than from “a priori assumptions” as other methodologies utilised (Glaser & Strauss, 1967, p. 6). They contended that GT would produce a hypothesis grounded in data (Glaser & Strauss, 1967) thus bridging the gap between theory development and empirical research through a merger with quantitative and qualitative research approaches in social research (Charmaz, 2014; Glaser & Strauss, 1967). Glaser came from a positivist quantitative background whilst Strauss was experienced in qualitative research and was exposed to the philosophies of pragmatism and symbolic interactionism (Charmaz, 2000). It is stated that both men had personal accounts of bereavement as each had lost one parent. Their personal experiences of death also contributed to their appreciation and development of GT (Emmel, 2013).
3.4.5 Divergent trajectories of GT: Glaserian, Straussian and Constructivist (Charmaz)

There was a schism in GT procedures between the founding fathers, which related to Strauss’ departure from certain concepts, and inclusion of others. As such, Glaser is known as staying true to the original, classic or traditional model of GT (Glaser, 2001). It adopts an inductive approach. As such, classic GT requires the researcher to remain open-minded, free from preconceived notions, which can allow the theory to freely emerge from the data (Glaser & Strauss, 1967).

The division between Glaser and Strauss was due to their opposing views of verification as an outcome of GT analysis (Heath & Cowley, 2004; Walker & Myrick, 2006). Firstly, Strauss collaborated with Juliet Corbin and changed his stance of an inductive approach and included a deductive component at the latter stages of research and theory development (Strauss & Corbin, 1990). This relates to axial coding and coding paradigms and is centred on the philosophy of pragmatism and SI. He provided guidelines about data analysis, which he felt could be used as a guide for researchers (Strauss & Corbin, 1998). Strauss’ premise for inclusion of deductive reasoning was to allow for broader contextual factors to be elicited, which facilitates differing explanations for the emerging theory. Glaser referred to Strauss’ inclusion of deductive reasoning as betrayal to the common cause of GT. Glaser’s stance was solely on inductive reasoning as core to GT. He postulates that this would ‘force’ data into “preconceived concepts” rather than allow them to emerge naturally from the data (Glaser, 1992, p. 3-4). However, Strauss’ method enables both inductive and deductive approaches to be used to yield a substantive, middle-range or formal theory (Corbin & Strauss, 2015).

Secondly, Strauss incorporated the use of the literature in its early stages, which the traditional GT form rejects (discussed fully in 3.5.4.2) (Strauss & Corbin, 1998). Strauss highlights the importance of examining the literature in its early stages. Firstly, he posits that this can enable the researcher to have considerable background knowledge in context to the research phenomena. Secondly, research phenomena can be identified and refined from the literature. Thirdly, research questions can be formulated in relation to the research phenomena under investigation. Fourthly, the literature can sensitise and stimulate thinking through comparing and contrasting interpretations with current data. And lastly, Strauss postulated that a review of the literature helps towards theory development (Strauss & Corbin, 1998).
Strauss also changed the perspective of GT by including the theory of SI (Strauss & Corbin, 1998). George H. Mead (1926) and Charles H. Cooley founded SI (1902/2009), although Herbert Blumer, a student of George H. Mead coined and developed the term in the literature (Blumer, 1969). SI stems from pragmatism and is used mainly in social sciences. It is a micro-level theoretical framework in sociology that is based on three assumptions and three premises outlined below and sixteen assumptions (see Appendix 3).

These assumptions are:
- Individuals construct meaning via interactions
- Relationships exist between individuals and society
- Self-concept motivates behaviour (Blumer, 1969).

The three premises are:
- Humans act based on meanings they ascribe to things
- These meanings arise through social interaction that one has; and
- Meanings arise through social interaction with others and society.

SI seeks to explain human behaviour through meanings individuals ascribe to these. It focuses on process, such as consequences and contingency; and processes such as language, symbols, perceptions and interactions (Corbin & Strauss, 2008). It also gives insight into individuals’ inner thinking as an inner dialogue and enables meanings and interpretations to emerge when interactions occur with others (Reeves et al., 2008). Strauss posits that whilst all existing realities are impossible to capture, he included symbolic interactionism to capture all possible variations and complexities of the experiences of the ‘real world’. These include interactions and events, multiple factors, the locality of experiences in relation to social, political, cultural, gender, informational and technology (Corbin & Strauss, 2008).

3.4.6 Versions of GT

Due to the schism previously described and an emergence of a contemporary version, there are three different types of GTs presented in the literature. These are the Glaserian or classic GT (originally Glaser and Strauss; and is now solely Glaser) (Glaser, 2002), Straussian (Strauss and Corbin) GT (Corbin & Strauss, 2015) and Constructivist GT (Charmaz, 2006). Straussian GT has been discussed. I will now give an overview of Classic and Constructivist GTs and a summary of their unsuitability for the current
study. Then I discuss the core underpinnings and differences between them and provide supporting reasons why Straussian GT was most appropriate for the aims and objectives of this study.

3.4.7 Classic (Glaserian) GT

The original version of GT known as classic GT is fundamental to data (Glaser, 2002). Glaser is seen as staying true to the GT (Classic), since Strauss’ departure (discussed in 3.5.1). Glaser’s stance on GT is fundamental to ‘all is data’, which highlights that everything concerning the phenomena should be seen as data (Glaser, 1978; 2001). These include observations, interviews and field notes. Hence data analysis is quite loose allowing the theory to emerge naturally from the data (Glaser & Strauss, 1967). Glaser claims that the researcher should focus on the data and ask this core question “what do we have here?” to know what is happening (Glaser, 2001). Glaser posits that the theory should emerge and should not be “forced”. As such unstructured interviews are utilised in classic GT, the use of a topic guide is opposed and the role of the researcher in the research process is passive and neutral (Glaser, 2001). Classic GT was not utilised for this study due to its restricted use of predefined phenomena to be examined, the research questions and the literature; the neutral role of the researcher and loose coding procedures (Glaser, 2001). These are discussed in further detail in 3.6.

3.4.8 The Constructivist (Charmaz) GT

Kathy Charmaz, who was a student of Glaser and Strauss, developed the constructivist GT. Her criticisms of the other two GTs were in relation to Glaser’s positivist stance and exclusion of the dynamics between participants and the researcher, and Strauss’ “prescriptive” coding process (Charmaz, 2006). Charmaz follows a relativist/constructivist stance in that reality is socially constructed and is not only dependent on the meanings and interpretation of data but is heavily impacted by interactions between the researcher and participants (Charmaz, 2006). Glaser criticized the underlying principles of constructivist position are in no way related to GT. He posited that Charmaz’ contributions, such as coding, delimiting and sampling are descriptive and irrelevant to the goal of conceptualisation (Glaser, 2002, p. 13). Bryant supports Charmaz position, by arguing that the researcher is not independent in the research process but influences the analysis and theory development through their constructions of beliefs and values (Bryant, 2002; Bryant & Charmaz, 2007).
Strauss died prior to the emergence of Charmaz constructivist GT methodology. However, he posited that GT is subject to “change with the times” (Strauss & Corbin, 1994, p. 276). Corbin, as spokesperson for Strauss contends that he may not have supported the constructivist paradigm (Corbin & Strauss, 2008). Charmaz supports the use of initial literature review but offered flexibility towards this. On one hand she acknowledges that delaying the review can help to “avoid importing preconceived ideas and imposing them on your work” (Charmaz, 2006, p. 165). On the other hand, she suggests that conducting an initial review of the literature can help researchers sensitise concepts and position themselves in relation to the phenomena under study (Charmaz, 2000). Constructivist GT was not utilised for this study due to conflicting views of the use of preliminary literature, exclusion of the literature during analysis and the belief that realities between the researcher and participants are shared (Charmaz, 2000; 2006). This is further discussed in 3.6.

3.4.9 The core underpinnings of the three versions of GT

All three versions of GT share theoretical sampling, theoretical saturation, comparative analysis (constant comparison), theoretical sensitivity, memo writing and substantive versus formal theory as core underpinnings (Corbin & Strauss, 2008; Charmaz, 2006; Glaser, 2002).

Theoretical sampling is the process in which data is collected for the trajectory of the research. As data is collected and coded during the research process, the gaps that are identified may call for further evidence in ‘a particular sphere’ or change the direction of the study, whereby further data collection is warranted. Selecting the sample based on the simultaneous collection of data is called theoretical sampling (Glaser & Strauss, 2014). Theoretical saturation is the process of data collection whereby the analysis is exhausted, and no new data emerges (Glaser & Strauss, 2014). Constant comparison is the process through which data is coded via conceptual labelling, higher-level concepts and categories and comparing of these occur constantly from the commencement of data collection, throughout the research process, and when the resultant theory emerges. At this point the emerging theory is compared with the literature (Holton, 2010).

Theoretical sensitivity enables the researcher to move from descriptive to an analytical level. This is achieved through an examination of relevant literature; through asking questions as the data emerge and may also include follow up interviews for further data collection. Data are also examined for
negative case analysis, that is, any instances that do not fit (Corbin & Strauss, 2015). Glaser and Strauss (1967) stated that the constant comparison process should “blur and intertwine continually, from the beginning of an investigation to its end” (Glaser & Strauss, 1967, p. 43). Memo writing is the process through which the researcher reflects on data collected and documents these during the trajectory of the research study. Writing memos “provides an immediate illustration for an idea”, (Glaser & Strauss, 1967 p. 108) and helps in theory development.

3.4.10 The distinctions between the three forms of GT

Previously, I discussed the core underpinnings of the three forms of GTs. Here, I discuss how these methodologies differ in relation to philosophical positions, coding procedures and use of the literature. I then highlight why I selected Straussian GT.

3.4.10.1 Philosophical positions:

In classic GT, Glaser asserts that it is a general research method (Glaser, 1998). He rejects SI and constructivism (Glaser, 2002). However, he ignores the philosophical assumptions underlying this methodology. As such Classic GT has been regarded as ambiguous (Bryant, 2002; Urquhart, 2002) with a consequential fear of “misinterpretation and misuse” (Moore, 2009; p. 9). Charmaz postulated that the classic GT takes a position of positivism/objectivism. Her stance was based on Glaser’s view of the researcher as a neutral observer and the objective measure of external reality (Charmaz, 2000). Glaser did not contest Charmaz’ assumptions (Charmaz, 2006). However, McCann and Clark (2003) argue that Classic GT follows a post-positivist paradigm and a critical realist ontological perspective. Strauss (1991, 1994, 1998) claims that he departed from a positivist realist ontology within the classic GT framework.

Straussian GT is based on a post-positivist and critical realist ontology that follows the philosophy of SI and pragmatism (Strauss, 1991; 1994; 1998), which Glaser rejects (Glaser, 2002). Straussian GT is based on the premise that “human grasp of reality never can be that of God’s” (Strauss & Corbin,
All GTs are constructed with relevance to culture, time and context and are considered “fallible,” and “provisional” (Strauss & Corbin, 1998, p. 4; 1994, p. 279). Charmaz supports the principles of SI and pragmatism but felt that these principles were overlooked in Straussian GT methodology due to the “overly prescriptive” coding procedures (Charmaz, 2006). The constructivist GT follows a relativist ontological framework, which Charmaz sees as a revamp to her impressions of neglect of SI and pragmatism in Strauss’ GT version (Charmaz, 2006). The epistemological position of the Constructivist GT is based on co-relationships and co-construction of knowledge between the participants and the researcher (Charmaz, 2000). Charmaz asserts that her methodology provides a “middle ground” between postmodernism and positivism (Charmaz, 2000, p. 510), and is contemporary (Charmaz, 2006). Her stance is considered questionable by current researchers (Kenny & Fourie, 2015) as the philosophical paradigms outlined are linked to postmodernist philosophy and is traced to Sophists (educators in the fifth and forth-century BC Greece) (Frame, 2008), which is considered neither contemporary nor unique.

3.4.10.2 Use of the literature

Classic GT suspends pre-existing or prior knowledge in order to position the literature when the research is nearing completion (Glaser, 2001). Glaser’s stance on the exclusion of research questions, research problem and theoretical background knowledge in its early stages was based on the premise that the researcher will remain uncontaminated and free of bias throughout the research trajectory (Glaser, 2001). He posits that theoretical background knowledge would ‘stifle’ the researcher’s abilities to generate categories, their properties and theoretical codes and “violate the basic premise of GT” (Glaser & Holton, 2004 para 46). This he believes will undermine the authenticity of the research process (Glaser, 1992). However, he posits that consulting the literature should only be done at the end of the study when constant comparison occurs (Glaser & Holton, 2004).

Nonetheless, the use of the literature is encouraged at every stage of the study, from conception to conclusion of the research study in Straussian GT (Corbin & Strauss, 2015). The researcher’s previous knowledge, experience and current literature are welcomed in context of the phenomena. Strauss contends that the use of existing knowledge guides theoretical sampling, addresses gaps in the literature, and inspires questions during analysis that guides the developing theory (Corbin & Strauss, 2015). However, Strauss warns the researcher to strike a balance when using the literature so that it does not constrain or stifle creativity and new revelation of the phenomena (Strauss & Corbin, 1990).
Constructivist GT endorses the use of the literature but restricts total immersion until after data analysis. Charmaz recommends that the comprehensive write up of the literature should be compiled in a chapter. This she believes would protect the researcher’s openness and creativity of the data (Charmaz, 2006).

3.4.10.3 Coding procedures

The coding procedures of Classic GT provide the foundation for the research process (Glaser & Holton, 2004; Holton, 2010). These follow two stages of coding: substantive coding and theoretical coding before a GT is discovered. Substantive coding occurs at two levels (open coding and selective coding). In open coding, data are analysed line-by-line and coded using a key word (Glaser & Strauss, 1967). These coded segments are then fragmented from the transcript, and conceptual labels are applied to them. Through constant comparison, these conceptual categories are compared, analysed, categorized and examined for relationships, until the emergence of a core category. At the selective coding level, the core category becomes the focus (Glaser & Holton, 2004). Through theoretical sampling, the interview questions are refined to collect and code subsequent data. This helps identify theoretical relationships with other categories and orders concepts to a higher level of conceptualization (Giske & Artinian, 2007; Jones & Alony, 2011). The final level of coding known as theoretical coding is based on inter-relationships of substantive concepts in relation to the extant literature as a means of comparison and conceptual mapping (Giske & Artinian, 2007). This enables the theory to be discovered from the data (Glaser & Holton, 2010).

Strauss and Corbin provide rigorous and highly systematic coding procedures to create a theory that stays close to the data in their version of GT. This consists of four stages: open coding, axial coding, selective coding and conditional matrix. They claimed that the robust procedure was to serve as a clear guide for novice and experienced researchers and “enhance the effectiveness of this methodology” (Strauss & Corbin, 1994, p. 273). Open coding follows the classic GT procedure in relation to line-by-line analysis, use of conceptual labels and questioning and comparative analysis. However, what differs is the demarcation between properties and dimensions of each category (Strauss & Corbin, 1990). Axial coding is the process of linking category and sub-categories as they emerge through relationships of causal conditions, context, intervening conditions, action/interactional strategies and consequences (paradigm model) (Strauss & Corbin, 1990). This refashions stand-alone categories as sub-categories to a higher-level conceptual category. In selective
coding categories are examined for inter-relationships with one another resulting in one main core category. At this level the researcher follows five steps in order to achieve conceptualization. These are story line, relating subsidiary categories around the core category in relation to a paradigm, relating categories at a dimensional level (Strauss & Corbin, 1990) validating relationships with the data and ensuring categories are refined through theoretical sampling whilst ensuring conceptual density (Strauss & Corbin, 1990).

And lastly a conditional matrix, which is an analytic aid, is constructed. Strauss states that this is not a fourth level of coding analysis. However, it is a framework that summarises and integrates the three levels of coding (Strauss & Corbin, 1990 p. 158-159), and enables the researcher to identify the conditions and consequences related to the phenomena. Eight levels of influence are within the conditional matrix: action pertaining to phenomena, interaction, group, individual, collective; sub-organizational, sub-institutional level; organizational and institutional level; community, national and international. This allows the researcher to outline the conditional trajectory of the incident and significant conditions activating the phenomena and consequences of this (Corbin & Strauss, 2008). Glaser criticized the coding procedures as being destructive (Glaser, 1992, p.3), whilst Charmaz stated that these were overly complicated (Charmaz, 2000).

Charmaz depicts the constructivist coding procedures as adaptable and flexible (Charmaz, 2008). It consists of two stages: initial/open coding and refocused coding. The first phase of coding employs Glaser’s two key questions of the data (What is the chief concern of participants?” and “How do they resolve this concern?”) (Charmaz, 2008, p.163). However, this approach codes for actions and potential theoretical cues rather than observing for themes. She advises on use of in vivo codes to maintain the language of participants and gerunds (noun form of verbs) to simplify definitions of what is happening (Charmaz, 2008). In the second stage of refocused coding, recurring codes are identified as provisional theoretical categories, and via the four underpinning concepts of GT, these are refined in relation to conditions and consequences. Charmaz highlights the significance of intensive interviewing as critical to the coding process (Charmaz, 2006). Glaser criticized Charmaz coding procedure as failing to conceptualize and being mainly focused on description (Glaser, 2002). However, Strauss supported the value of describing participants’ experiences as giving them a voice, however unlike Charmaz flexible coding procedures, Straussian GT uses a robust framework as a guide for researchers as well as to maintain rigor (Strauss & Corbin, 1990).
3.4.11 Why Straussian GT?

Straussian GT was selected as the methodology for the study for six main supporting reasons. Firstly, a key feature of GT is that it utilizes inductive enquiry that will provide the basis for identifying the research problem from participants’ perspectives (Walker & Myrick, 2006; Corbin & Strauss, 2008). Straussian GT allowed me to select the phenomena to be examined, unlike the classic GT, which does not commence with a pre-defined research context (Onions, 2006; Pickard, 2013).

Secondly, it is essential as a PhD student to review the literature extensively prior to collecting data, as a means of understanding what is already known about the topic and identify the missing gaps the study can fill. A review of the literature also follows ethical research guidelines (McGhee et al., 2007). The classic GT does not allow a preliminary review of the literature. The use of relevant literature in the early stages of the research process helps to develop theoretical sensitivity (Annells, 1997a, 1997b; Heath & Cowley, 2004). This follows the traditional research process in which a literature review informs the research question and theoretical framework guides the data collection and analysis, which is necessary to satisfy degree requirements (Elliott & Higgins, 2012). It is imperative that the literature be used at every stage of the study to enhance theoretical sampling, and inspire questions during data analysis, which would help the developing theory. The Constructivist GT forsakes the use of the literature during data analysis, which is critical to the phenomena (Charmaz, 2006).

Thirdly, Straussian GT utilizes SI, which takes into account both micro; contextual factors and the broader structural environment (macro conditions) that may influence the phenomena under study (McCann & Clark, 2003). Micro conditions refer to processes of interaction that occur within the immediate individual environment, which are relevant to the phenomena under study. Straussian GT examines broader social contexts or macro-factors (Strauss, 1998), such as socioeconomic status, educational background, gender, religion and culture that may influence individuals’ interactions and meanings of these. Strauss postulates that insight into macro-level interactions is "central to an understanding of social order" (Strauss, 1993, p. 242). In this case, female partners were included in the study as they too share this journey together with their spouses. An examination of their insights, perceptions, beliefs and interactions along PCa care pathways can facilitate rich understanding of the phenomena. In addition to the women, macro conditions also include political climate, economic and cultural conditions in context to the phenomena.
Reflexivity is also founded in SI (Stryker & Serpe, 1982), and is referred to as the ability of the researcher to explore her beliefs and motivations, and reflect on her own prejudices, assumptions and influences on the research process (Parahoo, 2014). Strauss advocates the use of reflexivity, which Glaser rejects as a distraction to the data, paralyzing, self-destructive and stifling (Glaser, 2001). Finlay (2002) describes the critical significance of reflexivity as a tool towards examining the researcher’s position, perspective and presence and the research participants’ contributions and interpersonal dynamics. Reflexivity also enables a log of research decisions to be built allowing for scrutiny and integrity (see 3.7), and also enables an evaluation of the research process (Finlay, 2002; Corbin & Strauss, 2008) (see 6.2.7). This is important to credibility (discussed in 6.2.8).

Fourthly, even though Straussian GT aims to unearth conceptualizations from the data, which are based on the interactions between those of the research environment and the researcher, the focus is more on the participants and not on the researchers’ beliefs and understandings (Creswell, 2009). This is unlike Constructionist GT, in which data is constructed by the researcher as a result of interactions with participants and the environment and is presented as ‘shared reality’ (Charmaz, 2003). It is important for the researcher’s beliefs to remain separate and distinct from those of the study participants, which Straussian GT permits through reflexivity, memo-writing and the use of the literature (Corbin & Strauss, 2015).

Fifthly, the Straussian GT also follows an epistemology involving the philosophy of pragmatism (Corbin & Strauss, 2008), which allows for an examination of process and consequences of the phenomena. This is quite significant as beliefs and meanings surrounding these are the primary focus of the study. This type of paradigm uses multiple practical and logical methods to answer the research questions with the focus on outcomes of the research. These are the practical implications, such as the actions, situations and consequences, with the goal of changing the phenomena (Denzin & Lincoln, 2018). This is useful to the research objectives as one of the main outcomes of this research is towards the development of key public health messages and policy development. Figure 9 shows a diagram representative of the actions, situations and consequences I was interested in for the current study. This links to Andersen’s (1995) model of care in understanding routes to diagnosis and associations with appraisal, help-seeking, diagnosis and treatment.
And finally, the Straussian approach has been widely used and is known for its methodological rigor (Cooney, 2011; Kenny & Fourie, 2015; Corbin & Strauss, 2015); even though critics have posited that this methodology is “overformulaic” (Melia, 1996 p. 370) and “overcomplicated” (Charmaz, 2000). However, this GT version has been said to be user friendly and provides clear guidelines for data analysis for novice researchers unlike other forms of GT (Ghezeljeh & Emami, 2009; Morse et al. 2002; Rolfe, 2006). For instance, classic GT has been said to be liberating (Heath & Cowley, 2004), which may promote confusion for novice researchers. The constructivist GT has been regarded as lacking “clear articulation” with regards to coding and analysis for novice researchers (Nagel et al., 2015 p. 369). Also, students have experienced a dearth of supervisors’ skilled in constructivist GT (Nagel et al., 2015).
3.5 Summary of research methodology

In this chapter, I described the ontology and underpinnings of GT and why this approach was selected compared to other methodologies (phenomenology and ethnography) that comprise the interpretivism paradigm. I then justified why the Straussian GT approach was utilised for this study. Table 13 is representative of the research methodology trail leading to my decision to use Straussian GT.
<table>
<thead>
<tr>
<th>Research aims</th>
<th>Classic GT (Glaser)</th>
<th>Constructivist GT (Charmaz)</th>
<th>Straussian GT (Strauss &amp; Corbin)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Selecting research phenomena</td>
<td>Does not commence with pre-defined research context</td>
<td>Not suitable for the current study</td>
<td>Enables the researcher to choose phenomena</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Enables the researcher to choose phenomena</td>
<td>Suitable for the current study and PhD research guidelines</td>
</tr>
<tr>
<td>Use of the literature</td>
<td>Does not allow a preliminary review of the literature</td>
<td>Not suitable for PhD research guidelines and ethics committee</td>
<td>Conflict towards using the literature in its early stages</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Does not use the literature during data analysis</td>
<td>Not suitable for aims of study</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Uses the literature to formulate research questions, develop theoretical sensitivity, assist with data analysis and theory development</td>
</tr>
<tr>
<td>Symbolic interactionism (SI)</td>
<td>Does not utilize SI</td>
<td>Not appropriate for the current study</td>
<td>Inappropriate for novice researchers</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Uses SI but does not give clear guidelines</td>
<td>Utilizes SI to identify both micro and macro conditions; this facilitates reflexivity</td>
</tr>
<tr>
<td>Role of the researcher</td>
<td>Independent to the research process</td>
<td>Not suitable to interpretivism</td>
<td>Not suitable for the aims of the study towards developing a theory that is representative of the participants views only, not suitable for policy making</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Interdependent; holds that the findings are co-constructed (both participants and researchers views)</td>
<td>Findings are representative of participants only. This is done through reflexivity, memo-writing and use of literature</td>
</tr>
<tr>
<td>Role of pragmatism</td>
<td>Does not utilize pragmatism</td>
<td>Unsuitability towards flexibility of research methods that best examines the phenomena</td>
<td>Utilizes pragmatism</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Does not utilize pragmatism</td>
<td>This highlights roles and consequences – one goal of the research study</td>
</tr>
<tr>
<td>Methodological rigor and use</td>
<td>Loose methodology, limited guidelines for novice researchers</td>
<td>Unsuitable for novice researchers</td>
<td>Unsuitable for novice researchers; those without experts in this methodology</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Fairly new type of methodology, limited expert supervisors to guide novice researchers, conflict with conducting this methodology</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Widespread use, clear guidelines, known for its reliability and trustworthiness</td>
<td>Appropriate for novice researchers like me, user friendly, useful guide for coding and help towards theory development</td>
</tr>
</tbody>
</table>

Table 13. Summary of research audit trail: choosing the research methodology of Straussian GT
CHAPTER FOUR – RESEARCH DESIGN, PROCEDURES AND METHODS

4.1 Introduction

In the last chapter I discussed the research paradigm of interpretivism that was utilised for the study inclusive of justifications for these. In this chapter I provide a description of the research design and methods for the study. These achieved the aims and objectives of the current study towards investigating the experiences of men newly diagnosed with PCa and their partners in TT. Firstly, I revisit the aims of the study and the research questions to be answered. I then discuss the research design I utilised in accordance to Straussian GT with applications of the literature, theoretical sensitivity, theoretical sampling, theoretical saturation, comparative analyses and purposeful sampling. For each phase I describe study locations, access, recruitment process, sampling and ethical principles and procedures upheld during the study trajectory. Secondly, I provide a description of the characteristics of research participants, data collection procedures and methods utilised throughout the study with justifications for these. Thirdly, I discuss steps taken to manage and analyse data in accordance with the Straussian GT framework. And lastly, I discuss methodological rigour and reflexivity of my research journey before providing a summary of this chapter. Pseudonyms are used for all gatekeepers, staff and participants throughout the study.

4.2 Aim of the study

This study aimed to investigate beliefs to diagnosis and treatment of men newly diagnosed with PCa; and the role and impact their partners play in cancer detection in TT. This research study also aimed to identify and contextualise issues faced by men newly diagnosed with PCa and their partners to develop a substantive GT (see chapter 7) that best support public health messages.
4.3 Research Questions

My research questions were as follows:

- What are newly diagnosed men beliefs, about their illness, during their journey to diagnosis and treatment of PCa in TT?
- What are partners’ beliefs of their spouses’ illness during their journey to diagnosis and treatment of PCa in TT?
- Why do men access healthcare services late in TT?
- What are the differences between the experiences of men and their partners in the two islands of TT?

4.4 Using Straussian GT

The application of Straussian GT has been utilised to examine the social processes through which men and their partners’ journey along routes to diagnosis and treatment for PCa in TT. The procedures of Straussian GT have been utilised following the principles of theoretical sampling, theoretical sensitivity, theoretical saturation and comparative analysis enabling contextual factors and both micro and macro conditions to be explored. Additionally, reflexivity has allowed the researcher to examine her beliefs and perspectives as separate to the research process. This included transparent accounts of being in the field (field-notes), research decisions during the trajectory of the study (research diary) and memo-writing enabling an evaluation of the research study as shown in the findings’ chapters. The theory that was generated from the study (chapter 7) is representative of multiple realities of participants’ experiences. The principles of Straussian GT were utilised at all stages of the research process and are discussed throughout this chapter.

4.5 Ethical approval

I obtained ethical approval from the University Ethics Committee at the University of Surrey, upon submitting my proposal (Letter of ethical approval Appendix 12). This contained the background to the study, aims and objectives and rationale, the preliminary literature review and research questions, the methodological process and methods including recruitment strategies, risk assessment (see
sample form in Appendix 10), participant information sheets (see Appendix 8 and 9), and interview
guides. Subsequently I obtained ethical approval from UWI (see Appendix 14); the RHA in Tobago (the
smaller of the two islands of TT) (letter in Appendix 15), and then from the NCRHA and NWRHA in
Trinidad (letters in Appendix 11 and 13). Figure 10 shows recruitment and the phases of data collection
for the study.

4.6 Gatekeepers and Access

I decided to collect data from Tobago first being the smaller of the two islands and its predominance
of African ethnicity in relation to PCa risks (TT Demographic Report, 2012). I felt a scoping visit was
not necessary as I had a fair knowledge of key gatekeepers and the research sites to target for access,
recruitment and data collection in TT. This was based on my prior visits to the hospitals for academic
meetings. Gate keeping has been described as an ongoing process that may occur in layers (Lee, 2005).
As such, I did advanced planning towards gaining access and kept informal telephone discussions with
key organizational and professional gatekeepers. Organizational gatekeepers refer to coordinators of
research whilst professional gatekeepers give access to staff (Benton & Cormack, 2000). I then
forwarded to them electronic copies of the detailed protocol and ethical approval from the University
of Surrey, including a research poster (see Appendix 16) that advertised the study. I obtained ethical
clearance after communicating with gatekeepers from TT and then made preparations to enter the
field. Holloway and Wheeler (2002) identified gatekeepers within health care research as exercising
power and control to protect potentially vulnerable people. As such gatekeepers can deny access to
conduct research for several reasons. Some of these are: lack of credibility or trustworthiness of the
researcher, which can be due to age, gender or inexperience; fear that the researcher might disturb
the clinical setting or cause undue stress to participants; the clinical area has been over-researched
recently or the research is sensitive in nature or unethical (Holloway & Wheeler, 2002). The middle
managers were quite keen to allow me entry to the research sites because of my professional self as
a cancer specialist nurse and lecturer in cancer care. The top-bottom hierarchical approach helped
towards the smooth running of the research study.
4.7  Research settings and sources of data collected

Oncology units and urology clinics were targeted for recruitment of research participants. Straussian GT advises that decisions surrounding the types of research settings and groups to be studied should be guided by the main research question (Corbin & Strauss, 2015). Hence, drawing from the research question, ‘What are the experiences of men newly diagnosed with PCa and their partners along routes to diagnosis in TT?’ the research target groups were chosen from oncology units and urology clinics across TT. Also, Straussian GT recommends that the number of research sites selected for a study should be based on access, available resources and time (Corbin & Strauss, 2008). Access to men from oncology units (n=2) and urology clinics (n=2) were significant to achieve a representative sample of the population in accordance to the phenomena under examination. There are five main oncology centres within TT that provide cancer care to the 1.36 million population for this nation (Government of the Republic of Trinidad and Tobago, 2016). I chose to recruit participants from the only existent oncology unit and urology clinic in Tobago and the largest cancer centre and urology clinic within the NWRHA and the NCRHA in Trinidad (see Introduction). This decision was based on three reasons. Firstly, sampling from three RHAs (outlined in Introduction p. 10) achieved a fair representation of the population of five RHAs within TT. Secondly, in accordance to the phenomena under examination, sampling men and their partners from these public health systems was representative of PCa care experiences in TT. And thirdly, this enabled comparative analyses of men diagnosed with PCa and their partners from both islands.

It was decided that qualitative data were the main sources of data to be gathered from the research in accordance to the research questions and phenomena under study. Straussian GT advocates that decisions surrounding the sources of data should be made on the premise that it has the maximum potential of capturing the kind of information desired for the research aims (Corbin & Strauss, 2008; 2014). The research study aimed to capture participants’ beliefs, perceptions and experiences of routes to diagnosis for PCa. Hence interviews and observations were selected as the main sources of data that depicted these types of information.

4.7.1  The oncology units in TT

The Tobago oncology unit forms part of the public health system that was opened in 2014. This is nurse-led and serves 60,000 population through self and professional referral and provides limited diagnostic and treatment regimes. Prior to this all patients from Tobago accessed the main oncology
units in Trinidad. This air-conditioned unit is situated in a peaceful location with a serene view of the oceans and mountainous landscapes and consists of one oncology consultant and house officer who works at a dual practice in Trinidad; two senior oncology trained head nurses, four oncology trained nurses, a clerical officer, a domestic worker and one attendant. This unit provides services such as DRE, PSA testing, chemotherapy administration, hormonal therapy, and teaching and counselling in a caring environment from Mondays through Saturdays.

The National Radiotherapy Centre (NRC), St James is the largest of the five cancer treatment facilities within public health systems in TT. This is a 24-hour emergency, inpatient and outpatient centre located in the northern hemisphere which has a 97 bed-capacity. Services offered here include pharmacy, radiology, rehabilitation, laboratory services and cancer treatment. Admission to this centre is through GP referral and emergency admission (Government of the Republic of Trinidad and Tobago, 2016). This centre was opened in 1979; however major developments have occurred from 2006-2015. This includes the commencement of treatment planning systems, refurbishment of operating theatres, and the advent of brachytherapy units and linear accelerators. Patients are admitted under a specific consultant and team at this centre for treatment and follow-up care (Trinidad and Tobago Organization of Medical Physicists, 2016).

4.7.2 The urology clinics in TT

The Tobago urology clinic is located near the capital in the main hospital, which provides diagnostic investigations and cancer treatment. Admission to the urology clinic is through referral from both public and private health systems. The other urology clinic was within the NCRHA. This clinic opens three days weekly for men with prostate health problems. Patients are admitted based on inpatient referrals and receive follow up care at this clinic. This clinic provides diagnostic investigations and referrals for cancer treatment via oncology wards at this NCRHA (Government of the Republic of Trinidad and Tobago, 2016).
4.8 Recruitment and sampling at TT research sites

This study employed both purposeful and theoretical sampling. Men and their partners were purposefully selected in relation to the research context, that is, men newly diagnosed with PCa (within six months of diagnosis) and their partners. The recruitment for the research sites selection is outlined in Figure 10 on the following page. Men were recruited through oncology staff, gatekeepers and the use of a research flier through the eligibility criteria as shown in Table 14.

<table>
<thead>
<tr>
<th>Inclusion criteria</th>
<th>Exclusion criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>English-speaking men of any age (residents of TT).</td>
<td>Non-English-speaking men.</td>
</tr>
<tr>
<td>Diagnosis of PCa within the last six-months to a year.</td>
<td>Diagnosis of PCa less than 6 months and beyond a year/diagnosis with a different type of cancer.</td>
</tr>
<tr>
<td>No evidence of mental illness or debilitating physical co morbidities or ill health.</td>
<td>Evidence of mental illness or physically debilitating co morbidities or ill health.</td>
</tr>
<tr>
<td>Partners of these men (18 years and above).</td>
<td>Partners of men that were not newly diagnosed with PCa (6 months to a year) or have spouses that are diagnosed with other types of cancer; below 18 years of age.</td>
</tr>
</tbody>
</table>

Table 14. Eligibility criteria for the current study
Figure 10. Flow chart of recruitment process and data collection

- **Recruitment of potential participants**
  - Oncology staff/Gatekeepers/Research flier
  - Access to patient database/Face-face interactions at clinics
  - Partners recruited through men

- **Potential participant attends recruitment meeting (collective & individual) within 1 week**
  - Consent form shown
  - Study details provided
  - PIS form given

- **Researcher contacted by phone (within 24-48 hours)**
  - Participant indicated interest in research
  - Interview scheduled

- **Demographic details and written consent obtained. Interview conducted**
  - Phase 1 (Tobago): Semi-structured interviews - Men (26 approached, 25 interviewed, 1 drop out)
    - Focus group - Partners (8 approached, 4 interviewed)

- **Phase 2 (Trinidad): Semi-structured interviews men (n=26); partners (n=12)**
  - All participants approached interviewed, No drop-outs
This study occurred via two phases. Phase 1 of the study was conducted in Tobago, which lasted for approximately 5 weeks. This was inclusive of 2 weeks towards gaining access and recruitment of potential research participants and 2-3 weeks for data collection (see Figure 10). I sourced potential research participants from the medical database with the help of professional gatekeepers in accordance to the eligibility criteria (Table 14). This information enabled me to have accurate information about patients’ diagnosis and staging and current treatment plan. However, this information was used for verification of patients’ diagnosis and not shared with participants (see reflexivity section). Partners were recruited through the men. I conducted semi-structured interviews (n=26) with men and one focus group interview with partners (n=4) in August to September of 2015.

Phase 2 of the study was conducted in Trinidad, which lasted 3 weeks. This was inclusive of one day towards gaining access, one week towards recruitment of potential research participants and 2 weeks for data collection (See Figure 10). Men and partners were accessed through face-to-face interactions whilst attending clinic appointments. I had no access to patients’ files. I conducted semi-structured interviews with both Trinidad men (n=26) and their partners (n=12) in April to May of 2016, following the same procedures as outlined in 4.6 and 4.7. As outlined in the Introduction chapter and in 2.6.4, it was important to interview a large sample of men from both islands to obtain a heterogeneous sample of men that were representative of different socioeconomic backgrounds, educational levels, religious and cultural differences and access to oncological services across islands. This enabled data saturation to be achieved.

4.8.1 Characteristics of TT research participants

Tables 15 and 16 show characteristics for TT participants with ages of participants ranging from 42-85 (men) and 40-80 (women). Men were diagnosed with co morbidities, such as DM, HTN and cardiac conditions. The research sample was representative of various ethnicities, socioeconomic backgrounds and religious groups from Tobago (men: n=25; partners: n=4) and Trinidad (men: n=26; partners n=12). Pseudonyms (code-names) were used for all participants for anonymity and confidentiality of information in accordance to ethical principles as discussed in 4.11.
<table>
<thead>
<tr>
<th>#</th>
<th>Name/Age</th>
<th>Marital Status</th>
<th>Occupation/Level of education</th>
<th>Religion/Ethnicity</th>
<th>Diagnosis</th>
<th>Partner</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Adam, 53</td>
<td>M</td>
<td>Labourer/No education</td>
<td>Pentecostal/African</td>
<td>Metastatic PCa; HTN</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Alex, 71</td>
<td>CL</td>
<td>Gardener/primary education</td>
<td>Baptist/African</td>
<td>Stage IV/bilateral orchiectomy/</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Stan, 68</td>
<td>S</td>
<td>Labourer/secondary education</td>
<td>Pentecostal/African</td>
<td>Metastatic PCa, uncontrolled HTN</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>Pete, 77</td>
<td>W</td>
<td>Retired noise detector/secondary education</td>
<td>Baptist/African</td>
<td>Stage 11 PCa</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>Tim, 64</td>
<td>M</td>
<td>Retired Police officer/Tertiary education</td>
<td>Catholic/African couple</td>
<td>Stage 2c – diagnosed privately/ radiation therapy, HTN/asymptomatic</td>
<td>Lin, 60, Primary education</td>
</tr>
<tr>
<td>6</td>
<td>Chris, 66</td>
<td>M</td>
<td>Retired fire office/secondary education</td>
<td>Pentecostal/African</td>
<td>Metastatic PCa</td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>Luke, 58</td>
<td>M</td>
<td>Retired police officer/Secondary education</td>
<td>Pentecostal/African</td>
<td>Stage 11 PCa (diagnosed privately)</td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>Mark, 68</td>
<td>CL</td>
<td>Business owner/Secondary education</td>
<td>Catholic/African</td>
<td>Metastatic PCa</td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>Clement, 54</td>
<td>M</td>
<td>Farmer/Labourer/Primary education</td>
<td>SDA/African</td>
<td>Stage 11 PCa</td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>Floyd, 77</td>
<td>W</td>
<td>Farmer/Primary education</td>
<td>SDA/African</td>
<td>Stage 11 PCa, bilateral glaucoma/cataract, cardiac pathology</td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>Baxter, 70</td>
<td>M</td>
<td>Farmer/Primary education</td>
<td>SDA/African</td>
<td>Metastatic PCa</td>
<td></td>
</tr>
<tr>
<td>12</td>
<td>Kinsley, 63</td>
<td>M</td>
<td>Driver/Secondary education</td>
<td>SDA/African</td>
<td>DM, Stage 11 PCa</td>
<td></td>
</tr>
<tr>
<td>13</td>
<td>Dan, 57</td>
<td>M</td>
<td>Watchman</td>
<td>Catholic/African</td>
<td>DM; HTN, Metastatic PCa</td>
<td></td>
</tr>
<tr>
<td>14</td>
<td>Cameroon, 72</td>
<td>M</td>
<td>Retired Principal/tertiary education</td>
<td>Catholic/Mixed</td>
<td>Stage II PCa (diagnosed privately)</td>
<td></td>
</tr>
<tr>
<td>15</td>
<td>Kodi, 46</td>
<td>M</td>
<td>Labourer/secondary education</td>
<td>SDA/African</td>
<td>Stage III PCa</td>
<td></td>
</tr>
<tr>
<td>#</td>
<td>Name/Age</td>
<td>Marital Status</td>
<td>Occupation/Level of education</td>
<td>Religion/Ethnicity</td>
<td>Diagnosis</td>
<td>Partner</td>
</tr>
<tr>
<td>----</td>
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<td>----------------------------------</td>
</tr>
<tr>
<td>16</td>
<td>Jason, 60</td>
<td>D</td>
<td>Labourer/primary education</td>
<td>SDA/African</td>
<td>Stage II PCa</td>
<td></td>
</tr>
<tr>
<td>17</td>
<td>Cain, 71</td>
<td>M</td>
<td>Gardener/primary education</td>
<td>Christian/African</td>
<td>Stage III PCa</td>
<td></td>
</tr>
<tr>
<td>18</td>
<td>Pat, 70</td>
<td>M</td>
<td>Farmer/Primary education</td>
<td>Christian/African</td>
<td>Stage IV PCa</td>
<td></td>
</tr>
<tr>
<td>19</td>
<td>Harry, 87</td>
<td>M</td>
<td>Labourer (retired), No education</td>
<td>SDA/African</td>
<td>Metastatic PCa</td>
<td></td>
</tr>
<tr>
<td>20</td>
<td>Glen, 72</td>
<td>M</td>
<td>Separated/Retired engineer</td>
<td>Pentecostal/African couple</td>
<td>Stage 1 PCa</td>
<td>Jewel, 62, Tertiary education</td>
</tr>
<tr>
<td>21</td>
<td>Wes, 77</td>
<td>M</td>
<td>Farmer/ No education</td>
<td>SDA/African</td>
<td>Metastatic PCa, DM, HTN</td>
<td></td>
</tr>
<tr>
<td>22</td>
<td>Paul, 72</td>
<td>M</td>
<td>Farmer/ Primary education</td>
<td>SDA/African</td>
<td>Stage III PCa</td>
<td></td>
</tr>
<tr>
<td>23</td>
<td>Greg, 72</td>
<td>M</td>
<td>Retired health officer/Secondary education</td>
<td>SDA/African couple</td>
<td>Stage III PCa</td>
<td>Tamara, 55, Secondary education</td>
</tr>
<tr>
<td>24</td>
<td>Damien, 58</td>
<td>M</td>
<td>Labourer</td>
<td>SDA/African</td>
<td>Metastatic PCa</td>
<td></td>
</tr>
<tr>
<td>25</td>
<td>Matt, 55</td>
<td>M</td>
<td>Driver/No education</td>
<td>Christian/African couple</td>
<td>Stage IV PCa</td>
<td>Ria, 58, Secondary education</td>
</tr>
</tbody>
</table>

Table 15. Characteristics of Tobago research participants (M=Married, S=Single, D=Divorced, W=Widower/CL=Common Law, SDA=Seventh Day Adventist)
<table>
<thead>
<tr>
<th></th>
<th>Name/Age</th>
<th>Marital Status</th>
<th>Occupation/Level of education</th>
<th>Religion/Ethnicity</th>
<th>Diagnosis</th>
<th>Partner</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Alan, 66</td>
<td>M</td>
<td>Retired teacher/Secondary education</td>
<td>Pentecostal, African</td>
<td>Unaware of diagnosis</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Dereck, 51</td>
<td>M</td>
<td>Health officer, Secondary education</td>
<td>Christian, Mixed</td>
<td>Stage II PCa</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Justin, 54</td>
<td>M</td>
<td>Labourer, Primary education</td>
<td>Catholic, Mixed</td>
<td>Stage III PCa</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>Terrence, 77</td>
<td>M</td>
<td>Retired office worker, Secondary education</td>
<td>Baptist, African couple</td>
<td>Stage 11 PCa (unsure)</td>
<td>Wilma, 72, pensioner, Primary education</td>
</tr>
<tr>
<td>5</td>
<td>Frank, 64</td>
<td>M</td>
<td>Retired salesman, Secondary education</td>
<td>Catholic, African couple</td>
<td>Unaware of diagnosis</td>
<td>Petra, 55, clerical worker,</td>
</tr>
<tr>
<td>6</td>
<td>Kane, 65</td>
<td>M</td>
<td>Retired accountant, Tertiary education</td>
<td>Muslim, Mixed</td>
<td>Advancing PCa</td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>Nat, 68</td>
<td>M</td>
<td>Labourer, no education</td>
<td>Pentecostal, African, East Indian</td>
<td>Stage III PCa (diagnosed privately)</td>
<td>Natasha, 50, clerical officer</td>
</tr>
<tr>
<td>8</td>
<td>Adrian, 58</td>
<td>M</td>
<td>Business owner/Secondary education</td>
<td>Catholic, Mixed couple</td>
<td>DM, unaware of prostate diagnosis</td>
<td>Cheryl, 62, retired school teacher, housewife</td>
</tr>
<tr>
<td>9</td>
<td>Eric, 80</td>
<td>M</td>
<td>Retired teacher, Secondary education</td>
<td>SDA, Mixed, East Indian</td>
<td>Advanced PCa</td>
<td>Paula, 70, housewife</td>
</tr>
<tr>
<td>10</td>
<td>Tom, 50</td>
<td>CL</td>
<td>Labourer, no education</td>
<td>Christian, African</td>
<td>Unaware of diagnosis</td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>Tyrell, 54</td>
<td>M</td>
<td>Unemployed, retired taxi driver, secondary education</td>
<td>Muslim, African, Mixed</td>
<td>Metastatic PCa</td>
<td>Tia, 52 Primary school teacher</td>
</tr>
<tr>
<td>12</td>
<td>Tony, 45</td>
<td>M</td>
<td>Carpenter, secondary education</td>
<td>Pentecostal, African, Mixed</td>
<td>Stage III PCa</td>
<td>Naomi, 50, private school bus driver</td>
</tr>
<tr>
<td>13</td>
<td>Bas, 62</td>
<td>CL</td>
<td>Retired labourer, primary education</td>
<td>Pentecostal, Mixed, African</td>
<td>Unaware of diagnosis</td>
<td>Charity, 53, private business owner</td>
</tr>
<tr>
<td>14</td>
<td>Trevor, 67</td>
<td>M</td>
<td>Pensioner, no education</td>
<td>Catholic, Mixed</td>
<td>Unaware of diagnosis</td>
<td></td>
</tr>
<tr>
<td>15</td>
<td>Chase, 70</td>
<td>M</td>
<td>Pensioner</td>
<td>Pentecostal, African</td>
<td>Unaware of diagnosis</td>
<td></td>
</tr>
<tr>
<td>#</td>
<td>Name/Age</td>
<td>Marital Status</td>
<td>Occupation/Level of education</td>
<td>Religion/Ethnicity</td>
<td>Diagnosis</td>
<td>Partner</td>
</tr>
<tr>
<td>----</td>
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<td>---------</td>
</tr>
<tr>
<td>16</td>
<td>Lee-Ping, 60</td>
<td>M</td>
<td>Community Activist, Business owner, secondary education</td>
<td>SDA, Chinese, Mixed</td>
<td>Stage II PCa</td>
<td>Patsy, 56, Secondary education, carer</td>
</tr>
<tr>
<td>17</td>
<td>Leo, 60</td>
<td>M</td>
<td>Business owner, Tertiary education</td>
<td>Pentecostal, Mixed couple</td>
<td>Metastatic PCa</td>
<td>Jane, 58 Tertiary education, business owner</td>
</tr>
<tr>
<td>18</td>
<td>Willo, 70</td>
<td>M</td>
<td>Pensioner, no education</td>
<td>Christian, African couple</td>
<td>Unaware of diagnosis</td>
<td>Theresa, 66, Pensioner</td>
</tr>
<tr>
<td>19</td>
<td>Randy, 67</td>
<td>W</td>
<td>Carpenter, private business owner, tertiary education</td>
<td>SDA, African</td>
<td>Stage III PCa</td>
<td></td>
</tr>
<tr>
<td>20</td>
<td>Clarence, 70</td>
<td>M</td>
<td>Engineer, private business owner, tertiary education</td>
<td>Pentecostal, Mixed</td>
<td>Unaware of diagnosis</td>
<td></td>
</tr>
<tr>
<td>21</td>
<td>Colin, 47</td>
<td>M</td>
<td>Carpenter, secondary education</td>
<td>Hindu, East Indian</td>
<td>Stage III PCa</td>
<td></td>
</tr>
<tr>
<td>22</td>
<td>Xavier, 59</td>
<td>M</td>
<td>Private business owner, secondary education</td>
<td>Pentecostal, Mixed</td>
<td>Stage I PCa</td>
<td></td>
</tr>
<tr>
<td>23</td>
<td>Ronny, 65</td>
<td>M</td>
<td>Joiner, primary education</td>
<td>SDA, African</td>
<td>Unaware of diagnosis</td>
<td></td>
</tr>
<tr>
<td>24</td>
<td>Rick, 50</td>
<td>M</td>
<td>Carpenter, primary education</td>
<td>SDA, African</td>
<td>Unaware of diagnosis</td>
<td></td>
</tr>
<tr>
<td>25</td>
<td>Roland, 55</td>
<td>M</td>
<td>Carpenter, primary education</td>
<td>SDA, East Indian</td>
<td>Unaware of diagnosis</td>
<td></td>
</tr>
<tr>
<td>26</td>
<td>Seth, 62</td>
<td>CL</td>
<td>Labourer/Primary education</td>
<td>Hindus, East Indian couple</td>
<td>Unaware of diagnosis</td>
<td>Sandy, 66 Pensioner, no education</td>
</tr>
</tbody>
</table>

Table 16 shows characteristics of Trinidad research participants (M=Married, CL=Common Law, SDA=Seventh Day Adventist)
4.9 Theoretical sampling, theoretical saturation and theoretical sensitivity

In Straussian GT, the emerging concepts direct further data collection in accordance to the principles of theoretical sampling and not the number of participants (Corbin & Strauss, 2008). Hence, the sampling path is not known in advance as the data collected and analysed directs subsequent data to be collected. Straussian GT postulates three ways that the researcher can gather data. This can be purposeful that relates to categories, their properties and dimensions; systematically through one person or place; or via convenience, that is, whoever volunteers to participate (Corbin & Strauss, 2008). These three ways of data gathering were employed for the study. Men and partners were selected firstly via purposeful sampling in order to obtain a sample representative of those diagnosed with PCa and their spouses that can offer valuable insight to the phenomena under study.

Convenience sampling was also utilised as some men and their partners chose the dates that were suitable for them to be interviewed, which were based on their clinic appointments. However, theoretical sampling occurred after conducting the first interview in Tobago and evolved as the research progressed. This enabled a systematic collection of data based on concepts. These were examined in relation to indicators and how they varied under different conditions. These were driven by selecting participants that enabled variations and representations of multiple realities to be achieved (Corbin & Strauss, 2008). For example, an examination of men’s experiences pertaining to socioeconomic status and educational background enabled various perspectives of the phenomena. This is described more fully in 4.7.3.

4.10 Interview guide

My initial review of the literature in accordance to Straussian GT enabled me to construct interview guides based on the research questions (see Appendix 4 and 5). These were accomplished through supervisory guidance. The interview guides were based on broad topics that were related to the phenomena and research questions under investigation. A review of the literature also facilitated a theoretical background and theoretical sensitivity (Corbin & Strauss, 2015). Strauss acknowledges that an initial literature review helps to refine the research questions and ultimately the interview
questions for the study (Corbin & Strauss, 2015). As such the broad topic areas of the interview guide were in relation to experiences of men newly diagnosed with PCa. Some of these areas focused on symptom experiences, onset of symptoms, and appraisal and help-seeking actions (see interview guide. Even though these topic areas were used as a general guide, I asked specific questions during the interview based on participants’ contributions. Hence the interview guides did not restrict the flow of the interviews as shared by participants. Interviews also facilitated freedom of speech. Due to the GT process, I refined the interview questions as the research study progressed since the interview is usually shaped and re-shaped to satisfy the principles of theoretical sampling, comparative analysis and theoretical saturation (Corbin & Strauss, 2015). Section 4.7 discusses how I conducted interviews through Straussian GT, and interviewing techniques utilised.

The interview guide was constructed into four main sections: pre-interview, introductory, main, and close of interview as shown in Table 17.

<table>
<thead>
<tr>
<th>Topic guide</th>
<th>Research questions</th>
<th>Content</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre-interview</td>
<td></td>
<td>Greeting, refreshments, signing of consent form, demographic details</td>
</tr>
<tr>
<td>Introductory</td>
<td></td>
<td>Tell me a little about yourself</td>
</tr>
<tr>
<td>Main interview</td>
<td>What are the experiences of men and their partners along routes to diagnosis for PCa in TT?</td>
<td>Pre-symptom experiences</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Awareness and knowledge</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Symptom experiences</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Help-seeking actions</td>
</tr>
<tr>
<td></td>
<td>What are newly diagnosed men and their partners’ beliefs, of their illness, along their journey to diagnosis and treatment of PCa in TT?</td>
<td>Beliefs and perceptions</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Interactions with staff</td>
</tr>
<tr>
<td></td>
<td>Why do men access healthcare services late in TT?</td>
<td>Social support/network</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Treatment experiences</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Roles of women</td>
</tr>
<tr>
<td></td>
<td>What are the differences between the experiences of men and their partners in the two islands of TT?</td>
<td>Diagnosis experiences</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Health/illness beliefs</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Help-seeking beliefs</td>
</tr>
<tr>
<td>Close of interview</td>
<td></td>
<td>Summary of interview</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Clarification of key areas</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Any additional information or questions</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Thanks for attending and follow-up</td>
</tr>
</tbody>
</table>

Table 17. Questions for Interview topic guide
4.11 Ethical procedures

There are three basic ethical principles in the conduct of research involving human participants. These are: need for full disclosure, need to ensure confidentiality is maintained and the need to ensure that participation is voluntary (Depoy & Gitlin, 2016). These principles were upheld for all research participants for the trajectory of the study.

4.11.1 Informed consent

Obtaining consent from participants prior to participation in the research study was critical. Informed Consent is not only related to signing a form, but it is a process as it relates to full disclosure. Informed consent pertains to voluntary agreement to participate in research, an understanding of the research study and risks involved, and their rights (Depoy & Gitlin, 2016). Even though the PIS (see Appendix 8 and 9) contained all information related to informed consent, participants were informed throughout the study that they had the right to refuse to participate, withdraw or omit what was said.

4.11.2 Confidentiality, anonymity and data protection

Confidentiality is one of the core principles in protecting human research participants (Depoy & Gitlin, 2016). The researcher received training in ethical procedures prior to the conduct of the study and has experience in conducting qualitative research. All aspects of confidentiality were stated in the PIS and discussed with participants. Each participant was informed about the members of the research team, and that they only would have access to data obtained from the study.

In order to maintain confidentiality certain steps were followed. A code name was assigned to each participant at the commencement of the study. This contributed to a master list of coded names, which was maintained for tracking purposes. Moreover, these strategies ensured that participants’ identities were protected, and information provided would not be linked to demographic details. All telephone communication during recruitment and follow-up were conducted in a private environment and names were not used so as to protect identity. Interviews were conducted in a quiet and secure room at the clinic sites in which privacy was maintained.
4.11.3 Data protection

Participants were informed that all data were kept in secure storage/password protected and would only be accessed by those involved in the study. Data was protected according to Data Protection Act (1998). All data related to the research study were either stored in a locked cupboard (with access only to the researcher) or password secured to protect participants’ identity and preserve confidentiality of information. These included tape recorders, transcripts, demographic forms, consent forms, research diaries, memo-scripts and coding programmes and schemes.

4.11.4 Minimising harm

Prior to the start of the interview, participants were advised to report any ill feelings or emotional distress during the course of the interview. They were also advised that counselling was available should they require this. As such, all participants were monitored throughout the interviews for signs of ill health or emotional upset. One participant became emotionally upset during the interview and requested to withdraw from the study. Other participants that experienced emotional distress were offered an opportunity to take a short break, recompose themselves and the interview recommenced at their request. Most of the participants asked questions relating to the PSA test, diagnosis and treatment to which I answered to the best of my ability. Other questions, such as financial concerns and specific concerns related to treatment were referred to the lead nurse.

4.12 Interviews

On the day of the interviews I reminded participants about their right to withdraw from the study and consent forms were signed therein (see Appendix 7 for sample consent form). I conducted interviews (semi-structured and focus group) with Tobago research participants in August to September of 2015 and Trinidad participants in April-May of 2016. Each interview lasted for 1-2 hours. I audio-recorded all interviews to capture data as expressed by participants. Effective communication strategies were utilised for all interviews. I conducted semi-structured interviews with TT men (n=51) and Trinidad partners (n=12) and focus group interviews with Tobago partners (n=4)) and further discussed in 4.7.3 and 4.7.3.2.
4.12.1 Demographic data

At each interview I completed a demographic form in which I recorded a code name, age, gender, diagnosis, marital status, religion, educational level; occupation and socioeconomic status (see Appendix 6). These contextual information or macro factors were fundamental to symbolic interactionism which underpins Straussian GT in understanding context, meanings within relationships and interactions as previously discussed (Corbin & Strauss, 2015).

4.12.2 Recording of interviews

All interviews were recorded on ONY ICD-PX440 stereo IC digital voice audio-recorder, which has microphones for audio enhancement and a USB port for charging and uploading of data to a computer. Immediately after each interview the recordings were transferred to a password-protected computer. This facilitated transcriptions and data analysis (discussed in 4.9). The audio recorder was kept in a locked cupboard during fieldwork.

4.12.3 Semi-structured interviews

I conducted semi-structured face-to-face interviews with TT men and Trinidad partners at their convenience in relation to clinic-venue and time. This was either at an assigned room at the oncology unit or at the main hospital. I commenced each interview by asking men the question, ‘Can you tell me a little of yourself?’ before progressing to ‘Can you share your experiences when you first noticed something was wrong?’ This open-ended question facilitated an unravelling of the journey from the initial symptom experience to the present moment. I ensured that the body of the interview captured all aspects of the phenomena in relation to the guide. Probing was used for other areas based on the direction of the interview. I ended the interview by asking, ‘Is there anything else you would like to share before we close?’ This was an indicator that the interview was coming to an end. As data was collected, the focus of subsequent interviews followed emerging concepts from initial data analysis.

Theoretical sampling allowed me to follow through on leads that were important for the study. For example, the first interview conducted highlighted experiences from the perspective of one man from a lower socioeconomic status. This triggered the question, ‘How do the experiences of men from
higher socioeconomic background compare to those from lower socioeconomic background, and,

‘What are the similarities and differences in experiences among men of lower and higher socioeconomic backgrounds? It was important to interview men from both high and low socioeconomic backgrounds to view how this factor influenced experiences along routes to diagnosis for PCa. Corbin and Strauss (2008) highlights that constant comparison allows properties and dimensions of relevant concepts to be identified. Another question asked of the data was regarding men that experienced private health systems and clinical trials as the initial sample were representative of mostly experiences of public health systems. Hence, data collection and analysis occurred simultaneously and cumulatively throughout the trajectory of the study as subsequent data to be collected was dependent on the analysis of previous data collected, as guided by Straussian GT. Theoretical sampling enabled categories to be fully developed allowing theoretical saturation and theoretical sensitivity to be achieved. Theoretical sampling occurred when each category was examined thoroughly in regard to its various properties and dimensions in varied conditions. Theoretical saturation is the point at which no new data emerges. Theoretical sensitivity allowed me to become more in tune with meanings coming out from the data. Even though theoretical saturation was arrived at in Tobago, it was decided that theory generation could be enhanced through the addition of interviews with participants from Trinidad (Strauss and Corbin, 2008).

Constant comparison goes hand-in-hand with theoretical sampling and aids theoretical sensitivity and theoretical saturation (Corbin & Strauss, 2015). Constant comparison was achieved through comparing data for similarities and differences (Corbin & Strauss, 2015). This occurred at the property and dimensional level in relation to the technical literature. Corbin and Strauss (2008) highlight the importance of using technical literature for the processes of constant comparison. It can be utilised for making comparisons and enhance theoretical sensitivity once the researcher is familiar with relevant materials. The technical literature can also stimulate questions during analysis and areas for theoretical sampling as shown with the concept of socioeconomic backgrounds. And lastly, the technical literature can be utilised to confirm findings or highlight where there is a dearth of evidence to support or explain phenomena (Corbin & Strauss, 2015).

The nontechnical (research diary, memo-writing) literature was also utilised as primary data and supplemented interviews and observations. This was useful for the processes of constant comparison, theoretical sensitivity and theoretical sampling (Corbin & Strauss, 2015). For example, one observation recorded in my research diary was the use of my cultural self as one of my multiple
identities in the field (see 7.3). This concept was useful for me to examine the researcher-participant relationship and how this influenced data collection.

Strauss highlights that the researcher is the instrument of data collection (Corbin & Strauss, 2015). In addition to self-reflexivity, he postulates key attributes that are also critical to the researcher’s expertise. These are appropriateness, authenticity, credibility, intuitiveness, receptivity and sensitivity (Rew et al., 1993). These are discussed in greater detail in the next section. All 26 Tobago men that voluntarily agreed to participate in the study attended semi-structured interviews. However, the transcript of one interview was withdrawn from the study, due to emotional upset and his request not to use the audio-recorder. He was referred for counselling. Semi-structured interviews were successfully conducted with a total of 25 Tobago men.

4.12.3.1 Justification for semi-structured interviews

Unstructured and structured interviews were seen as inappropriate for the current research study. As previously highlighted (3.5.2.1) Classic GT methodology supports unstructured interviews to maintain the passive role of the researcher and the absence of an interview guide (Glaser, 2001). It was critical to use relevant and current literature to frame the broad topics and subsequent questions asked in the interviews. Unstructured interviews may also result in participants discussing other matters that may be irrelevant to the phenomena (Denzin & Lincoln, 2011). Structured interviews are pre-set questions that are more suitable for quantitative research as they restrict in-depth exploration of phenomena (Kvale & Brinkmann, 2009). Additionally, this type of interview may affect theoretical sampling as data collected sensitizes the course of subsequent data to be collected (Corbin & Strauss, 2015). As such, structured interviews restrict the researcher from asking differing questions based on the data collected and limits contextual data.

The decision to utilize semi-structured interviews for men and focus group interviews for partners was based on supporting evidence. Strauss highlights that “there are no one standard set of methods equally useful for every research step” (Strauss & Corbin, 1998 p. 30). As this methodology follows a pragmatist paradigm, he asserts that various available techniques can be utilised to achieve desired results (Creswell, 2003; Strauss & Corbin, 1998). A diagnosis of cancer and in relation to gender-specific health problems is considered sensitive to individuals (Nobis et al., 2007). It was important to ensure that men felt comfortable to share their experiences. One-to-one interaction with men and myself was deemed most appropriate towards building a rapport, which facilitated an in-depth
exploration of their story (Denzin & Lincoln, 2011). Since the methodology is grounded in symbolic interactionism (Corbin & Strauss, 2015), interactions between participants and me as the researcher were key to gathering data. As such face-to-face interactions enabled me to utilize effective verbal and nonverbal communication strategies, such as proper tone of voice, eye contact and body language towards rapport building. This also allowed observations of participants’ tone of voice, facial expressions and expressed words, which facilitated the data collection process. The semi-structured interviews enabled me to explore topics that were relevant to the phenomena under study whilst maintaining flexibility towards identification of cues that led to new insights of other areas not covered on the interview guide. This facilitated data collection of ‘reliable and comparable data’ (Corbin & Strauss, 2015).

4.12.3.2 Focus group interviews with Tobago partners

I conducted one focus group interview with four partners in a private room at the hospital, which lasted for 2 hours. The interview guide was structured around women’s accounts of their spouses’ experiences as well as their perceptions and experiences of these. I started the focus group interview by asking each partner to introduce and share a little about herself before progressing to the question, ‘Can you share your experience of your spouse/partner being ill?’ My prior experience conducting focus group interviews helped me to stimulate discussions. Utilising effective communication strategies, I ensured that each participant contributed to the discussion, and utilised probing to gain deeper insight.

4.12.3.3 Justification for focus group interviews with partners

Focus group interviews were selected for the partners initially as there is evidence that demonstrates its effectiveness towards obtaining rich data from populations with a shared interest (Barbour, 2017). These women shared similar experiences of having a partner/spouse diagnosed with PCa. Another reason for selecting focus group interviews was based on capturing macro-conditions as highlighted in symbolic interactionism (Corbin & Strauss, 2008). In relation to partners, these centred on their perceptions, roles, meanings of these to self, spouses and others. Interactions between partners during the focus group interviews enabled me to observe multiple views of the phenomena. As such various meanings were explored through interactions between participants (Denzin & Lincoln, 2011). The focus group method was also used as an instrument to gather data through participants’ discussions. This occurred as each participant’s contribution triggered reflections and sharing of
others’ experiences, which highlighted similarities and differences among partners’ accounts (Denzin & Lincoln, 2011).

Eight partners gave verbal consent to participate in the focus group interviews, however only four attended. Reasons for non-attendance were in relation to lack of support from Tobago spouses towards participating in the study and the mode of data collection. These partners expressed preference for one-to-one interviews. Their reasons were based on privacy and confidentiality. Due to these requests, one-to-one interviews were conducted thereafter with partners (Trinidad). Strauss contends that the researcher should be flexible towards data collection and adapt to methods that can generate rich data throughout the research process (Corbin & Strauss, 2008). Upon ethical revisions, a new topic guide was completed for face-to-face semi-structured interviews with partners. This was structured utilising emerging concepts from the focus group interviews in keeping with the principles of theoretical sensitivity. As grounded theory is inductive (Corbin & Strauss, 2015), the one-to-one interviews enabled concepts and themes to emerge naturally from the data. This is discussed more fully in 3.15. At the end of each interview (both one-to-one and focus-group), I invited any additional information, summarized participants’ contributions and sought clarifications on any area that was not captured fully. This enhanced the rigor of the study.

4.12.4 Researcher interview skills and techniques

Professional experience in qualitative interviewing has been said to be important towards data sensitivity (Corbin & Strauss, 2008). Since qualitative interviewing requires the researcher to enter into participants’ world, it was important for a rapport to be developed to facilitate an interactional exchange of dialogue (Gupta & Awasthy, 2015). This was accomplished through good eye contact, active listening, right tone of voice and correct posture that made participants feel comfortable (Denzin & Lincoln, 2005). However, these skills also facilitated relationship building on a more personal level which challenged professional boundaries between myself and participants during interviews (Allan & Arber, 2018). I managed these situations through maintaining my professional role. For example, participants desired to discuss personal information such as my marital status, family life and questions that pertained to their cancer diagnosis. Questions that related to my personal life were answered politely drawing them back to the research. Those that pertained to their cancer diagnosis were deferred to the doctor or head nurse.
I had experience in conducting qualitative interviews prior to data collection for the current study. Whilst experience can aid in accelerated understanding of some aspects of the research, Strauss and Corbin (2014) warns that experience has the potential of preventing analysts from interpreting data correctly due to preconceived notions, knowledge in the field and assumptions. As a lecturer in the field of cancer care prior to the start of the research I had a wide understanding of PCa from a theoretical standpoint. However, I had limited exposure to current clinical aspects of PCa care at the centres in TT. This enabled me to enter the research field with a fresh outlook. Straussian GT maintains that data collected should not be contaminated by the researcher’s perceptions (Corbin & Strauss, 2008). This limited knowledge of clinical care was useful towards conducting the research without knowledge of what occurs within the centres.

4.13 Data analysis

Here I discuss the processes of data analysis in accordance to Straussian GT methodology. The key data analysis procedures that occur within this type of methodology are: theoretical sampling, comparative analysis, theoretical saturation, memo writing (code notes, theoretical notes, and operational notes), analysis diagrams, field notes, open coding, axial coding, selective coding, paradigm model, conditional matrix, and substantive or formal theory development (Strauss & Corbin, 1998; 2008). I first discuss the transcription process of the interviews, before I explain details of coding, and how rigor was maintained throughout the study.

4.13.1 Transcription of the interviews

Transcription is the first step toward data analysis and tends to be overlooked in context to theoretical assumptions (Bird, 2005). It “reflects goals and definitions” (Duranti, 2007 p. 44), and is an interpretive and selective process (Davidson, 2009) that requires skill in the grounded theory process (Corbin & Strauss, 2008). I transcribed the digitally recorded interviews in verbatim as data collection commenced. The SONY ICD-PX44O stereo IC digital voice audio-recorder permitted me to slow down, rewind and upload the data to my password-protected computer via its USB port. This facilitated checking of data for accuracy and clarity against the recordings, which strengthened the rigor of the study. The transcription process is an intensive one. Strauss and Corbin emphasize the researcher should familiarize themselves with transcripts through reading which facilitates labelling phenomena,
and discovering and developing categories (Corbin & Strauss, 2008). My decision to self-transcribe all interviews rather than resort to professional-transcription was based on three reasons. Firstly, it was important for me to become immersed in the data, which gave greater insight into participants’ worldview and in turn promoted theoretical sensitivity and the theoretical sampling process (Corbin & Strauss, 2008). Secondly, it allowed me to be in control, thus capturing accuracy and significant details such as pauses, laughter, vocal expressions that may have been missed by a professional transcriber who may not have a background in qualitative research. This enabled me to contextualise the data in relation to participants’ stories. And thirdly, this decision safeguarded possible epistemological implications for inexperienced transcribers such as handling of sensitive data and the impact of these on emotional wellbeing and transcription-related errors (Forbat & Henderson, 2005). Examples of a transcribed interview can be found in Appendix 22.

There are two choices towards the approach to transcriptions in data analysis, which are related to the epistemological assumptions and the research paradigm that undergirds the study (Lapadat, 2000; Jaffe, 2007). These are naturalism and denaturalism. Naturalism seeks to capture all aspects of data, such as words as well as “idiosyncratic elements of speech” (Oliver, 2005 p. 1273). These include pauses, stutters and involuntary vocalizations. Denaturalism captures only the spoken words, and thus removes the idiosyncratic elements (Oliver, 2005). My transcribing followed the process of denaturalism as it was most suitable to address the research questions and follows the Straussian GT methodology (Corbin & Strauss, 2008). Additionally, as the study is guided by interpretivism, it was important to record key aspects of idiosyncratic elements that may have influenced “theoretical constructions” (Lapadat, 2000 p. 208). My research diary and member checking helped me to reflect on and locate the meanings of these in context of the phenomena. Two entries from my research diary can be seen later in this chapter.

Member checking was used to enhance the trustworthiness of qualitative findings. This can be done through returning transcripts or the interpretations of transcripts to participants or conducting follow-up interviews to verify or validate accuracy and meanings of data (Doyle, 2007). There are advantages and disadvantages that I considered in the decision to utilize member checking. Member checking can enhance rigor of the study since participants can confirm or refute interpretations and greater insight of the phenomena can be gained. The participants can observe their contributions to the research study, which can promote transparency, respect and trust during the research trajectory (Corbin & Strauss, 2008). However, some disadvantages are that this may be time-consuming for the researcher and participants may feel coerced to agree with the researcher during this process (Birt, 2016). This
ethical issue of participant coercion may affect the trustworthiness of findings (Birt, 2016; Harvey, 2015; Koelsch, 2013). Having expert guidance with interpretations of findings throughout the study enhanced rigor. Due to the interpretivist paradigm that was followed, the researcher aimed to discuss the interpretation of the first three-transcribed/analysed interviews with participants to validate findings and facilitate theoretical sampling and comparative analysis (Harvey, 2015). This was achieved with the first-two-transcribed/analysed interviews in each country, as participants were too busy attending clinic appointments and felt that this process was too timely and tedious for them. However, the researcher’s interpretations of the interviews that were sent to participants were accurate. The confirmed data interpretation assisted with interview guide revisions, and focus of subsequent data collection, which in turn promoted rigor.

4.13.2 Coding software

I completed a foundation-training course in the use of QSR Nvivo 10 coding software. There are advantages and disadvantages of using the Nvivo coding software. The coding software has been known to save time and assist towards sorting, managing and organizing large quantities of data. It also facilitates data analysis for all stages of the grounded theory methodology utilised for the study and enables an audit trail to be completed (Corbin & Strauss, 2008). For example, the full text of each transcript was uploaded and imported into the Nvivo software package that enabled me to review data collected and make initial notes. Nvivo enabled searches, word counts, linkages with transcripts and memos, and observations of patterns within the data to be performed. Coding and grouping into codes, then into concepts, categories and the coding scheme were some functions that were supported by Nvivo coding software (discussed more fully in the following sections). NVivo allowed creation of nodes each time a concept was identified from interview data (Bazeley, 2007). This facilitated transparency of data analysis process (Welsh, 2002) and hierarchy of relationships (tree-nodes) between concepts and categories.

However, there are limitations associated with the use of this software. These include excessive time to familiarise and learn the steps and processes involved towards managing and analysing data and researcher dependence on the software (Corbin & Strauss, 2008). Learning the Nvivo computer software was a requisite for my PhD training programme. This training enabled me to understand and utilize the software in data analysis. Nvivo has also been known to create too many nodes and skip coding/insufficient response to nodes during the auto-coding process. I experienced this limitation in
the initial stages of auto coding. As such I did manual analysis concurrently with Nvivo coding to counteract these limitations. My decision for manual coding and analysis was also based on three supporting reasons. Firstly,Straussian GT methodology advocates the researcher’s substantial role in the research process (Strauss & Corbin, 1990). The Nvivo software coding should not replace the researcher’s critical role in the analysis process (King, 2004). This includes decisions regarding collation, identification of patterns, synthesis of data and interpretation. Secondly, manually sorting and coding the vast volume of data through colour coding and copy and pasting were time consuming, but these enabled me to stay close to the phenomena under study (Strauss & Corbin, 1998). And thirdly, Strauss posited that coding software has “the potential to change the quality of the theory” (Strauss & Corbin, 1998 p. 278). Hence concurrent manual coding was important to enhance the robustness of the study. The processes of coding following Straussian GT methodology inclusive of Nvivo are discussed in the proceeding section.

4.13.3 Stages of coding

The Straussian GT methodology involves a systematic rigorous coding system that enhances the effectiveness of data analysis. Straussian GT analysis is designed to “spell out the procedures and techniques” and to assist “persons who are about to embark upon their first qualitative analysis project” (Strauss & Corbin, 1994, p. 273). However, analysis within the rigorous coding system is not structured or rigid but is “free flowing” as these occur whilst enhancing rigor (Strauss & Corbin, 1998). Coding occurs via three stages: open coding, axial coding and selective coding (Strauss & Corbin, 1998). Even though each stage requires different level of abstract thinking, the researcher constantly moves back and forth between them (Strauss & Corbin, 1990). This inductive process enables a rigorous theory to emerge that best represents the phenomena (Strauss & Corbin, 1998).

Strauss specifies that coding procedures are designed to:

- Build rather than test theory.
- Provide researchers with analytic tools for handling masses of raw data.
- Help analysts to consider alternative meanings of phenomena.
- Be systematic and creative simultaneously.
- Identify, develop, and relate the concepts that are the building blocks of theory. (Strauss & Corbin, 1998 p. 13).
In 3.4.1.0 I gave an overview of Strauss GT methodology. I now present my data analysis with respect to this framework.

4.13.3.1 Open coding

This is the first step towards analysis of data via the Straussian GT methodology. Open coding simply means, “to open the text and expose the thoughts, ideas and meanings contained therein” (Strauss & Corbin, 1998 p. 102). Strauss defines open coding as “the analytic process through which concepts are identified and their properties and dimensions are discovered in data” (Strauss & Corbin 1998, p. 101). Open coding is critical to the progression of data analysis, as the other two steps (axial and selective coding) are dependent on this (Strauss & Corbin, 1998).

Strauss identifies several ways in which open coding can be done. Line-by-line coding or microanalysis is one form of open coding in which words and phrases of each interview transcript are examined in each line. In sentence or paragraph coding the researcher examines each sentence or paragraph asking the question, “What is the major idea brought out in this sentence or paragraph?” Document coding involves the perusal of the entire document (interview transcript) asking the question, “What is going on here?” and then later on for other transcripts, “What makes this document the same as, or different from, the previous ones that I coded?” (Strauss & Corbin, 1998, p. 120).

I decided to use line-by-line coding, which is considered the most time consuming of the three methods previously identified. However, it is the most generative and facilitates theoretical sampling and comparative analysis (Strauss & Corbin, 1998). After conducting the first three interviews, I transcribed them. I commenced my analysis of the data by listening to the recorded version of the first interview to get a general sense of the participant’s narrative. I then re-played the audio whilst I read the corresponding transcript. This allowed my conceptualizations to stay close to the data, and in connection to the research questions, which maintained authenticity of participants’ words and meanings (Corbin & Strauss, 2008). I then highlighted words or expressions that “stood out’, whilst pausing the audio-recorder. Some words that stood out for me in the first transcript was “nobody”, “alone”, “ignorance” and “by myself”.
Strauss advocates putting the analysis immediately into memos (Strauss & Corbin, 1998). As such, codes were then labelled and code notes (one type of memo) were written to reflect my initial thoughts generated for each line in the margins of the transcript (see line-by-line coding Appendix 17). I also highlighted words that were repetitive and “in vivo” expressions to stay close to the data, such as “big man cry”. This continued for the entire document. One in vivo expression that continued throughout other transcripts was “Nobody told me”. This enabled me to examine the proceeding documents and subsequent interviews for similarities, differences and relationships. Strauss emphasizes that categories emerging from the data and their relationships are the foundations of the developing theory (Strauss & Corbin, 1998).

I did not upload the document to the Nvivo coding software until I had read and open-coded the first three interviews. My reason for this was that I had some time before conducting the other interviews and my preference for manual handling of data concurrently with Nvivo permitted me to do so. I uploaded these into Nvivo and started the auto coding procedure, which resulted in “too many nodes formation” as previously discussed. Concurrent manual coding along with managing data via Nvivo helped me to refine codes, which were then grouped into categories, corresponding sub-categories and higher-order categories (Strauss & Corbin, 1990). Also, each category was examined for its properties (features or characteristics) and dimensions (frequency, intensity, degree or duration) (Strauss & Corbin, 1998). Microanalysis allowed me to have a sense of how categories related to each other. Strauss highlights that axial coding elaborates this process of identifying relationships among categories. However, these are initially seen during open coding (Strauss & Corbin, 1998).

Microanalysis known as the minute and careful examination of data occurs during open coding and axial coding (Strauss & Corbin, 1998). Strauss postulates that the experience and knowledge of the researcher promotes self-awareness and sensitizes him/her to issues, alternative explanations and properties and dimensions of emergent concepts in the data (Strauss & Corbin, 1998). Analysis of participants’ data, researcher’s interpretations of data and the interplay that occurs between the data and the researcher towards data collection and analyses are significant to Straussian GT methodology (Strauss & Corbin, 1998).

Meaningful discussions and insight into the data allowed codes to emerge, which minimized researcher bias. For example, the code ‘pain’ was examined in relation to properties and dimensions
in order to develop concepts. Adam’s appraisal, help-seeking, and treatment beliefs were highlighted in the open coding process. These were in relation to hegemonic masculinity norms, self-management practices and lack of knowledge and awareness of the need to seek help. Open coding was done for all emerging codes, which concluded the inductive stage of open coding.

4.13.3.2 Axial coding

Axial coding is defined, as “the process of relating categories to their subcategories, termed “axial” because coding occurs around the axis of a category, linking categories at the level of properties and dimensions” (Strauss & Corbin, 1998 p. 123). In axial coding data that were left “open” or fractured from the process of open coding are reassembled and categories are examined for how they “cross-cut and link” with each other (Strauss & Corbin, 1998 p. 124). Axial coding is a timely process in identifying relationships and making connections among categories. Strauss highlights that this stage is dependent on having readily available categories as intensive coding occurs around single categories (Strauss, 1998). However, categories are deemed provisional initially and are discarded if not supported by data (Corbin & Strauss, 2008). Each category highlights a single phenomenon that is significant to participants. This can either be a problem, an event or an issue. The relationships of categories are linked to their sub-categories as a means to gain a better understanding the phenomena (Corbin & Strauss, 2008).

Memo writing continued during axial coding. Strauss defines memo as “the researcher’s record of analysis, thoughts, interpretations, questions, and directions for further data collection” (Strauss & Corbin, 1998 p. 110). Writing memos move the analysis forward (Corbin & Strauss, 2008). In addition to code notes, theoretical and operational notes were performed at this stage (see Appendix 18-20). Theoretical notes are “sensitizing and summarizing memos that contain an analyst’s thoughts and ideas about theoretical sampling and other issues” related to the phenomena; whilst operational nodes are “memos containing procedural directions and reminders” (Strauss & Corbin, 1998 p. 217). Ongoing meetings were kept with my supervisor who is an expert in qualitative data analysis to discuss my memos, which facilitated theoretical sensitivity, theoretical sampling and comparative analysis.

At this stage, microanalysis and questioning the data utilising: Who? When? Why? What? Where? How? How much? and With what results? (Strauss & Corbin, 1998 p. 89, 90) was performed for each category (phenomenon). I moved from an inductive to a deductive stage in my analysis at this time. This facilitated contextualization and location of categories within a conditional structure. This also
enabled me to relate structure with process as a means to set the stage or circumstances in which these (problems, issues, happenings, events) occur in context to the phenomena (Strauss & Corbin, 1998 p. 127)

The paradigm model designed by Strauss and Corbin was utilised at this point which enabled refining of categories through clear demarcations of causal conditions, context, intervening conditions, action/interational strategies and consequences (Corbin & Strauss, 2008). For example, the concept ‘delay’ was further refined and examined for relationships with other concepts, which formed initial provisional categories, ‘isolation’ and ‘disconnect’. However, these were discarded as data collection and analysis continued and refinement ensued. The resulting category (see Appendix 18-20) ‘Disrupting the self’ took into account physical, emotional and social impact of the symptom experience.

Axial coding occurred over six months for each phase of the study. The paradigm model was utilised at this stage. I moved from an inductive stage to a deductive stage in my analysis at this time, as data were examined in relation to context in which they were embedded. This stage was critical in relation to the literature in highlighting categories that were relevant and specific to the research problem. Diagrams were created showing mapping of analytic concepts, and relationships throughout the analysis. This was instrumental towards sensitizing the researcher towards the phenomena and moved the analysis forward. Memos and diagrams were updated as analysis progressed. Strauss indicates that memos highlight when a category is saturated or well developed in relation to its properties and dimension (Corbin & Strauss, 2008).

4.13.3.2 Selective coding

Selective coding is the final stage of coding. It facilitates analytical descriptions of the core categories that validate the experiences of the research participants. Linkages and mapping of the data were symbolic for theory development as represented in the conditional matrix (Corbin & Strauss, 2008). This occurred over six months for each phase of the study. The time periods assigned for analysis were critical for accurateness, rigor, trustworthiness and reliability of findings. Additionally, word counts were utilised by counting specific events from Nvivo and field notes, which were significant to the evolving theory. This facilitated higher-level order abstraction and the emergent of a core category that was symbolic of the grounded theory (Corbin & Strauss, 2008). The core category was tested for its relationship to other ‘subsidiary categories. Strauss and Corbin postulate that the core category
should emerge through a hierarchal order commencing from conditions to phenomena to context to action, interaction and strategies, which leads to consequences. This stage of the process required constant revisiting of the data, conceptualizations and in context with the literature. This facilitated observations of relationships at a dimensional level and validation against the data. Further refinement of categories was done at this stage to ensure conceptual density through theoretical sampling (Corbin & Strauss, 2008).

The conditional matrix was then revisited and updated following the eight levels of influence as Strauss highlights for theory building: action pertaining to a phenomenon, interaction, group, individual, collective, sub-organizational, sub-institutional level, organizational and institutional level, community, national and international. This allowed a specific incident to be traced through these successive levels of the matrix to establish the conditional path (Strauss & Corbin, 1990). Strauss claims that this will help the researcher ‘identify significant conditions that activate the phenomena and the consequence arising from it’ (Strauss & Corbin, 1990).

4.14 Methodological rigor

There are certain criteria for judging the quality of research. The criteria that Strauss and Corbin highlights are: fit, applicability or usefulness of findings, concepts, contextualization of concepts, logic, depth, variation, creativity, sensitivity and use of memos (Corbin & Strauss, 2008 p. 9).

Fit relates to how the findings resonate with both the experience of the researcher as well as those of the research participants. An interview summary at the end of each interview, clarity and clarification of transcripts and member checking facilitated this process for the research participants that responded. This enhanced the trustworthiness of findings. Applicability or usefulness of findings pertains to whether the findings provide new insight and can develop policy and improve the knowledge base of a profession. The substantive theory (discussed in the proceeding chapter) is the first to be developed among this population and provides new insight into the beliefs and experiences of Afro-Caribbean men with PCa and their partners. This substantive theory also has implications for policy-development and practice.

Concepts refer to the substance of the findings towards establishing density and variation (Corbin & Strauss, 2008). Contextualization of concepts conveys in depth meanings and understanding of events
and participants’ experiences (Corbin & Strauss, 2008). My supervisor who is an expert in grounded theory methods guided the analyses and contextualization of concepts ensuring density and variation, in depth meanings and comprehensive understanding of data. An in-depth analysis of data collected from both samples from TT enhanced the rigor of the study. Logic denotes sense and clear flow of ideas and decisions towards findings, without leaving gaps (Corbin & Strauss, 2008). Depth signifies significance, richness and variation in findings that have the potential for implementing policy and practice (Corbin & Strauss, 2008). Selective reporting bias can affect the credibility of qualitative research. It is defined as reporting preferred or positive outcomes of research. This also refers to the exclusion of negative case representation that is reflective of all participants’ accounts (van der Steen et al., 2018). Straussian GT advocates variation when reporting findings that highlight differing participants’ views inclusive of negative cases that represent multiple realities (Corbin & Strauss, 2008). This was achieved by ensuring all participants views were represented by providing comparators during data analysis and searching the data for deviant cases. Excerpts depicting occurrences of the substantive theory that was generated from the data including negative case analyses are shown in Appendix 23. I followed the guidelines in Straussian GT methodology and through consistent and in depth analyses this enabled logic, depth and variation of findings (in chapters 5 and 6) to be achieved.

Evidence of memos reflects the analyses of the researcher’s insights, analytic questions and depth of thinking for the trajectory of the study (Corbin & Strauss, 2008). Sensitivity relates to whether the data drives the analysis without the influence of the researcher’s preconceived biases (Corbin & Strauss, 2008). Creativity describes new and innovative findings (Corbin & Strauss, 2008). Memos were completed and developed as the study progressed which enabled an audit trail of the trajectory of the study (illustrated in Appendix). I followed the principles of reflexivity and made entries in my research diaries and memo writing. This allowed me to reflect on my own personal biases and preconceived notions and sensitised me to the data (chapter 7), which in turn enhanced theoretical sensitivity. The findings reflect a range of views that were representative of participants’ shared experiences and deviant case representation (see chapters 5 and 6 and Appendix 23). The findings of this study are new and innovative and demonstrate the creativity of the researcher towards.

4.15 Credibility of the study

Corbin and Strauss (2008) also highlight eight conditions that pertain to the credibility of the study. These are methodological consistency, clarity of purpose, self-awareness, training in qualitative
research, sensitivity for the research topic, willingness to work hard, creativity, methodological awareness and a desire for conducting research.

Methodological consistency relates to the researcher’s ability to follow through (Flick, 2002, p. 219; Morse et al., 2015). Corbin and Strauss (2008) highlights that being consistent with the research design and procedures for the study as outlined in the research proposal establishes and maintains credibility. This also prevents ‘method slurring’ (Baker et al., 1992). Strauss and Corbin also postulate that the principles of GT such as constant comparison, theoretical sampling and saturation and concept development towards theory building should be wholly utilized in order to maintain the study’s credibility. The procedures and research design for the study were followed as outlined in the research proposal. This enhanced the study’s credibility.

Clarity of purpose, the researcher’s self-awareness and training in qualitative research methods were also referred to as important for the credibility of the study. Clarity of purpose refers to the researcher’s aim towards description or theory building, Corbin and Strauss (2008) emphasize that this should be clearly stated at the beginning of the study. Self-awareness denotes the researcher’s accounts of biases and assumptions throughout the research trajectory. I followed the principles of reflexivity and made entries in my research diaries and memo writing. This allowed me to reflect on my own personal biases and preconceived notions and sensitised me to the data, which in turn enhanced theoretical sensitivity and the credibility of the study. Training in qualitative research is identified as significant to the study’s credibility. Corbin and Strauss (2008) recognize the importance of being trained in the use of qualitative methods and analysis, which provides a sound research foundation. This enhances the credibility of the study, which reflects in theme-building, rich-thick description and in-depth analysis and interpretations. In the last section I identified my researcher skills and training in qualitative research methods.

Sensitivity for the research topic, a willingness to work hard and creativity were other conditions Corbin and Strauss (2008) pointed out as being essential for enhancing credibility. Being sensitive to the research topic refers to an empathic, honest and respectful engagement with research participants. It also emphasizes the intuitive abilities of the researcher to capture the experiences of participants through stepping into their shoes and understanding this from their perspectives. Corbin and Strauss (2008) establish that sensitivity contributes to richness and depth of the data, which enhances the credibility of the study. A willingness to work hard for the research trajectory is also an important condition that contributes to the credibility of the study. This refers to intensive
engagement with the data and following through with all the principles associated with GT). Creativity denotes being open to new ideas and flexible to utilize qualitative strategies in order to understand the meanings behind participants experiences. This includes a willingness to brainstorm, think about the data in new ways and time spent towards making theoretical comparisons.

The remaining two conditions that enhance the credibility of a study are methodological awareness (Seale, 2002, p. 108) and a desire to conduct research. Corbin and Strauss (2008) identifies that the researcher should be aware of all methodological and procedural decisions made including its implications. This also involves solving methodological problems if they arise. All methodological procedures and decisions were made with guidance from my supervisors throughout the trajectory of the study. And finally, the conduct of research should be motivated by the researcher’s desire for this and not for personal gain. As outlined in the Introduction, this research study aims to satisfy a critical development needs area within cancer care in TT and is not for personal gains. I now discuss my reflections on undertaking the research study in TT.

4.16 Chapter summary

This chapter described how the aims and objectives of the study guided the research design and methods that were utilised during the study. Data collection procedures were described in context of the phenomena. This included the construction and development of the interview guides as the study progressed, the conduct of semi-structured and focus group interviews with participants, and theoretical sampling to facilitate in depth and contextualised meanings of phenomena. Additionally, a detailed description of data analysis (Straussian GT methodology) was presented in relation to coding procedures: open coding, axial coding and selective coding. The key underlying principles of comparative analysis, theoretical saturation and sensitivity, memo writing, reflexivity, analysis diagrams, field notes, paradigm model, conditional matrix were utilised in accordance to Straussian GT methodology. Through this systematic and rigorous process, a substantive theory emerged that is representative of men and their partner’s experiences of PCa in TT. The findings are presented in the proceeding chapters.
CHAPTER FIVE – FINDINGS: MEN’S PRE-DIAGNOSIS EXPERIENCE OF PCA IN TT

5.1 Overview of routes to diagnosis and findings chapters

Over the next two chapters (5 and 6) I present men’s routes to diagnosis for PCa in TT, as shown in Figure 11. Men’s journey is representative of five categories: ‘Disrupting the self’, ‘Disconnected to Health Services’, ‘The Wall of Silence’, ‘Blame and Distrust’ and ‘Breaking the Silence’. Men’s accounts of their journey do not follow a linear path as highlighted in Andersen’s revised model of care (Walter et al., 2012). Rather, it follows a complex trajectory representative of routes to diagnosis for PCa as experienced by asymptomatic and symptomatic groups of men. I first provide an overview of TT men’s routes to diagnosis. I then provide a summary of each findings chapter.

Asymptomatic men’s journey represents those with a family history of PCa that were involved in separate prostate clinical trials through GP and self-referral. Due to provider silence with reports of the participants of non-reporting of diagnostic test results (PSA, DRE, bone scans and imaging) and diagnosis these men report that they withdrew from the clinical trials and recommenced their care at public and private health systems. Men that progressed through clinical trials presented via emergency admissions and were diagnosed with advancing prostate disease at both public and private health systems. Symptomatic men’s journey represents the PCa experiences of delayed help-seeking and self-managed symptoms; and those that were guided through networks of social contacts. Men that delayed medical help-seeking due to several factors presented to emergency health services with debilitating symptoms, some of whom were subsequently diagnosed with metastatic prostate disease. These factors were hegemonic masculinity norms; cultural, religious beliefs and practices; self-care beliefs and practices and perceptions of risk for PCa. Men that were guided by knowledgeable social contacts and lay networks experienced a smoother transition along care pathways and were diagnosed earlier with Stage I and II PCa.

The first chapter of findings describes men and their partners’ pre-diagnosis experiences. This illustrates the categories of, ‘Disrupting the self’ and ‘Disconnected to health services’. This highlights how men and their partners’ religious, cultural and family beliefs, traditions and practices and
hegemonic masculinity norms contributed to appraisal and help-seeking delays which resulted in delay in seeing medical help. Men’s pre-diagnosis experiences also illustrate how men’s lack of knowledge and awareness of the prostate gland and symptoms suggestive of PCa influenced their misinterpretations of bodily changes experienced during the symptom experience. The second chapter of findings describes men and their partners’ diagnosis and post-diagnosis experiences, as reflected in the categories of ‘The wall of silence’, ‘Blame and distrust’ and ‘Breaking the silence’. These portray participants’ accounts of silence whilst interacting with health care providers when engaging with health systems, which led to diagnostic and treatment delays. The roles of women and knowledgeable social contacts towards timely appraisal, accurate interpretation of symptoms and prompt medical help-seeking for men’s prostate problems are also elucidated in this chapter.

Participants’ names have been changed to preserve confidentiality and maintain anonymity. Direct quotations are used throughout these chapters to stay close to the voices of these participants. I discuss the categories in relation to TT men and their partners’ experiences and then highlight how these relate to each other along routes to diagnosis for these men in chapters 5 and 6.

This chapter discusses TT men’s pre-diagnosis journey for PCa that are representative of the categories, ‘Disrupting the self’ and ‘Disconnected to health services’. I first provide a summary of ‘Disrupting the self’ in relation to the experiences of asymptomatic and symptomatic men. I then discuss this category under the following headings: ‘Disrupting prostate care within clinical trials’ and ‘Symptomatic men and partners’ experiences of ‘Disrupting the self’. I highlight factors that both facilitated and impeded men’s appraisal of symptoms and help-seeking actions along these pathways to care.
Figure 11 is a diagrammatic representation of men’s experiences of routes to diagnosis for PCa in TT.

Grey represents asymptomatic men’s journey and yellow represents symptomatic men’s journey.
Blue represents shared journey for both groups of men and green represents the categories generated from the study.
5.2 Disrupting the self

This category represents men’s initial experiences along routes to diagnosis for PCa in TT as illustrated in Figure 11. These experiences are men’s accounts of events that caused major disruptions to their normal biography and expectations of prostate care. For men that were involved in clinical trials, this disruption pertained to their withdrawal from these trials and enrolment at other health services in response to provider silence experienced. This was in relation to non-reporting to the men of diagnostic test results such as the PSA, DRE and radiographic scans. Men’s withdrawal from clinical trials subsequently led to diagnostic and treatment delays for PCa. For these men, ‘Disrupting the self’ also represents their disrupted expectations of provider control towards detecting their PCa early and obtaining an early and better diagnosis, treatment and survival by being part of a trial.

For symptomatic men, the category of ‘Disrupting the self’ links with Bury’s framework of disrupted biography (Bury, 1982). This describes men’s tolerance of debilitating bodily changes suggestive of advancing prostate disease, such as severe back, bone and pelvic pains, urinary retention and erectile dysfunction and their reluctance to seek medical help for these symptoms until these became too burdensome to endure. This was evidenced as disrupting men’s ability to work and provide for their families; disrupting marital relationships and disrupting cultural and religious beliefs that pertained to prostate health.
Bearing debilitating symptoms led to men’s emergency presentation at public health systems. It also highlights factors underlying men’s tolerance of symptoms and reluctance in seeking medical help. These are hegemonic masculinity norms; cultural, religious beliefs and practices; self-care beliefs and practices, perceptions of risk for PCa and links with DM. These factors contributed to appraisal and help-seeking delays. I now describe men’s accounts of ‘Disrupting the self’ from each of the pathways identified. This is discussed under the headings ‘Disrupting prostate care within clinical trials’ and ‘Symptomatic men and partners’ experiences of disrupting the self’.

5.2.1 Disrupting prostate care within clinical trials

Harry and Mark’s experiences are described here. Harry explains how leaving the clinical trial disrupted his relationship with his family doctor. This resulted in delays in finding another doctor and recommencing his care at a private health system. And Mark describes how his expectations of provider control towards his prostate health were disrupted when he experienced symptoms suggestive of PCa.

Harry, a 73-year-old labourer was introduced to a clinical research trial through his family doctor. He explained that even though certain tests were done while in the programme, he experienced delays in getting the results of these tests. Harry’s wife, a nurse advised him to discontinue his attendance at the prostate research programme because of this.

‘He was my family doctor. He introduced the programme to me. He took the samples to check my PSA and I never got any results. I asked the clerk about it...she said but your results were sent in the post. I never got any postal results. Never mind I went there, and they finally got the thing and showed it to me. They said that my PSA was 3 or 4 or something like that (cough) and they called me again for some bone density test. I went, and I did that. And I asked about my PSA. They said its okay. And then I didn’t get any result from the bone scan. So, I spoke to my wife, she was a nurse at that time. She said don’t bother going back there if they can’t give you any results, so I had to start all over again and find another doctor. This was difficult because he was my family doctor for many years. I never continued with him as my family doctor. Eventually, I went privately.’ (Harry, Tobago).
Harry expressed dissatisfaction about the lack of communication of his diagnostic results from his doctor at the research programme. He reported that he experienced delays in getting information about his PSA test results and subsequently his bone scans. Harry’s experiences of provider silence caused him to discontinue his appointments there and recommence at a private health care system. Harry’s connection with his family doctor was disrupted after consulting with him for many years. A long-term relationship developed between a patient and a GP has been described as therapeutic that could result in breakdown or termination if one party’s identity feels threatened, as seen with Harry (Stokes et al., 2014). Harry’s withdrawal from the clinical trial also resulted in scheduling, diagnostic and treatment delays as he had to find another doctor and re-commence his care in the private health care system. Continuity of care has been described as a reflection of one dimension of quality care and critical to reducing hospital admissions (Deeny et al., 2017; Freeman & Hughes, 2010).

Similarly, Mark experienced disruptions in relation to his expectations of prevention of advanced PCa. Mark, a 68-year-old retired business owner stated that he had been enrolled at a clinical trial for 37 years. He shared his accounts of physical and emotional disruption in relation to his experiences of symptoms suggestive of PCa during that time. He perceived that any signs of PCa would have been detected early at the clinical trial.

‘I was there from since the inception of the programme for about 37 years... I was in my 30’s. I didn’t even reach 40 as yet. I heard about the programme and I decided to join early because the earlier you find cancer there is a better chance of survival as you could treat it early. They were taking blood and doing rectal examination with the finger and bone scans. While there I told the doctor that I had problems passing urine. They gave me some tablets to help pass urine. In 2013, my situation got worse, I started peeing blood. I felt unlucky. I felt that since I was being monitored there...the years that I have been going there on the programme, I should get a different experience. You don’t think so with so many years? I mean I was there because men were getting PCa and I joined. They call me every year and they did all the tests. They said they checking for PCa. I don’t understand that. I feel unlucky’ (Mark, Tobago).

Mark demonstrated an internal locus of control towards his prostate health. This served as a help-seeking facilitator for Mark. An internal locus of control has been defined as a belief that one could
influence events or outcomes (Ajzen, 2002; Ammirati & Nowicki, 2017). Mark’s knowledge of the survival rate for PCa when diagnosed and treated early motivated him to participate in the clinical trials. The data also describes Mark’s expectations of external locus of control, which is his expectation of joining the clinical trial as a means of establishing control of his prostate health through HCPs expertise and guidance. An external locus of control has been defined as a belief that events or outcomes are controlled by external forces (Ammirati & Nowicki, 2017), such as HCPs. External locus of control was found to be associated with trust in the patient-provider relationship due to patients’ perceptions of HCPs as powerful authority figures (Brincks et al., 2010). Mark’s objective was for his HCPs to detect PCa early so that it could be treated in a timely manner thus preventing advanced prostate disease. Mark’s enrolment also demonstrated a sign of trust in HCPs. However, his experiences of blood in the urine disrupted his expectations that his cancer was controlled. Mark described this as being unlucky. His experiences led to feelings of blame and distrust. This will be discussed further in 6.2.1 and 6.4.3. Symptomatic men and partners’ experiences of disruption are now discussed.

5.2.2 Symptomatic men and partners’ experiences of disrupting the self

Men in this study with serious symptoms linked to PCa, such as severe back, bone and pelvic pain; weak urine stream and difficult urination; numbness and weakness in the lower extremities and erectile dysfunction were found to be reluctant to seek help from medical services until their symptoms were advanced. Disruption pertained to physical effects of debilitating symptoms on self and on men’s ability to work and provide for their families, their beliefs and the emotions that were triggered in response to these bodily changes and the disruptive effects on marital relationships. Hegemonic masculinity played a significant role towards men’s reluctance to report their symptoms to health experts. An important aspect found in the data was the stoicism of men in relation to managing their symptoms themselves until they became so severe that they had to take action.

Partners accounts of men bearing symptoms and concealing emotions also points to hegemonic masculinity norms. This also links with Charmaz (1983; 1995) concept of ‘loss of self’ through which men adapt to bodily impairments due to a loss of self-identity and surrender to the ‘sick role’ that was brought on by disruptive symptoms that poses a threat to their masculinity. Disruptive bodily symptoms such as urinary retention and severe back pain that interfered with work becoming noticeable by others is inclusive of red-flag symptoms such as blood in the urine (haematuria is a symptom of advanced stages of PCa) were identified as help-seeking triggers for these men. I discuss
symptomatic men and partners’ experiences of disrupting the self under the following headings: Being strong and less prone to illness, Disrupting men’s self-care practices with regard to men’s cultural and religious beliefs, Hesitation in sharing beliefs about use of TH and the herbalist, use of the pharmacy, herbal use and religious teachings and beliefs, disrupting emotions and men and partners’ accounts of disruptions experienced in their relationships and the belief that diabetes mellitus (DM) was the cause of disruptive symptoms.

5.2.2.1 Feeling strong and less prone to illness

Here I describe how men adapted themselves to debilitating symptoms leading to delayed medical help-seeking. Adam’s role as breadwinner was disrupted after bearing debilitating bodily symptoms of back pain. Similarly, Ronny’s masculine stoic image caused him to bear his pains until these became overwhelming. He presented as an emergency admission. Alan and Lee-ping reported delaying help-seeking due to their perceptions that they were not at risk for being ill from prostate problems. For Alan this pertained to Black men being stronger than other ethnic groups, and Lee-Ping rationalizes his risk of PCa in light of his Chinese ethnicity.

Adam described how his pains became unbearable and disrupted his ability to work and provide for his family. His debilitating back and leg pains and weakness served as triggers for Adam to seek medical help.

‘I was good...then I was experiencing some pain that I wouldn’t wish for my worst enemy. Unbearable pain that could make a big man cry. At certain times I feel like I couldn’t walk, I couldn’t move. I was weak... But basically, what I used to experience was mainly back pain...just mainly back pain...until it was unbearable... I worked at... but I haven’t been working because of the illness, it was difficult...you could say...it took me about 3 months before I realize it’s really something, I should go to the doctor for...only when I couldn’t walk. I used painkillers but that didn’t work. With the sickness I was down...I was depressed about it. There are some things I never really shared with anybody when the pain was too severe...it’s like I could give up on life now you know. That’s how far it had me. I said to myself, I could bear it no more’ (Adam, Tobago).
Adam eventually visited his doctor when his pain became unbearable and he could not walk after 3 months. The emphasis that Adam gave to the extreme symptoms he was experiencing are clear from the data in that his pain was unbearable, and he was unable to walk, and he couldn’t move. Adam reflected his identity as a ‘big man’ and this is conforming to hegemonic masculinity norms, which dictates that men should be tough and put up with the pain like a big man and restrict emotions (Courtenay, 2000a; Courtenay & Keeling, 2000). The literature has shown that masculinity ideologies can negatively impact men’s health practices when they strive to demonstrate ideals that are expected of them by society. ‘Men don’t cry’ is one societal norm that men are expected to conform to, as seen with Adam. Masculinity ideologies can have implications for health seeking and reporting symptoms in a timely manner (Connell, 1993; Courtenay, 2000b; O’Neil, 2008). Adam’s disrupted body caused him to feel powerless as he described losing control of his ability to walk and thus work and provide for his family. Adam also described his emotional reaction of feeling depressed about the situation and not feeling he could share these feelings with anyone. He got himself to a situation where he was ready to give up.

Adam did not assign sufficient magnitude to his bodily changes until his pain interfered with his ability to work and provide for his family. Scott postulated that situational and social factors, demonstrated through conforming to societal norms such as masculine norms about bearing the pain affect how individuals interpret and manage bodily changes (Scott et al. 2013), as seen with Adam. This links with Bury’s biographical disruption and the significance of work to body image (Bury, 1982). This influenced his inability to link his symptoms to a serious health condition and contributed to delays in seeking help, despite regularly attending the hypertensive clinic.

Some men of African ethnicity held the belief that they were superior in physical strength and stronger than men of East Indian, mixed and Chinese ancestry, and as such were less prone to developing illnesses. Due to these beliefs, men perceived that bearing pain or ill feelings and stoicism were expected of them, which significantly delayed help-seeking.

Alan shared that Black men were expected to bear health problems without complaint in comparison to other ethnic groups in both islands. This was a cultural belief that was held among participants, including partners/spouses, which influenced help-seeking behaviours.
‘I think we sometimes feel that we black men are strong. At least that’s what slavery taught us. So, society expects us to bear our pains and our health problems. Maybe that’s why we don’t share how we feel even when we are really ill. What would people think? Nobody bothers about the Indians, the Chinese and the Spanish men. Those men would bawl and carry on and nobody thinks anything of it. But when we African men go to the hospital for a problem, we get everybody watching us... doctors and nurses too. They’re watching us in a funny way. I never really did anything about my back pain initially because of this’ (Alan, Trinidad).

Alan stated that he delayed seeking help for his back pains because of societal norms that Black African men were stronger than other ethnic groups. He highlighted differences in help-seeking beliefs and practices which he linked to slavery. He felt that African men were deterred from seeking help because of societal norms originating from slavery, which deemed that black men were stronger than other ethnic groups. He stated that while men from other ethnic groups were free to express sadness and pain through tears, men of African descent could not display their emotions. Alan stated that these societal/cultural norms extended to consulting health care providers, which may have also contributed to help-seeking delays. Alan’s experiences are supported by a study that found racial bias among laypeople and health care providers towards black men’s perceived higher ability to bear pain, based on perceptions of the black men’s skin being thicker than other ethnic groups (Hoffman et al., 2016). Additionally, a survey conducted in the US found that people with darker skin tones were perceived as being stronger than those of lighter skin tones (Wilson et al., 2017). Alan’s perceptions contributed to a longer time towards help-seeking and resultant diagnosis and treatment of PCa.

Lee-Ping shares his perceptions of feeling at low risk of developing PCa. Being of Chinese ethnicity, Lee-Ping also delayed help-seeking due to his perceptions of his risk of developing PCa being low. Lee-Ping indicated that his urine flow had slowed down. He had heard from his social network regarding PCa but felt that he was not predisposed to developing the disease. He highlighted that his friends influenced his interpretations about his bodily changes as being related to the prostate.
'I had problems with the urine. It slowed down at first. I have all the information people give me and who suffered with that. I knew that this affects African men so I didn’t think I could get this at first. You know men don’t really know much about the prostate as such. I didn’t know. It was Dr Martha, she is a friend of mines, she told me that this was the prostate and that I could get cancer too’ (Lee-Ping, Trinidad).

Lee-Ping shared about his lack of knowledge of the prostate. He felt that he was exempted from developing PCa because of his ethnicity. Lee-Ping described both lay people and health care professionals within his network that were instrumental towards his appraisal of symptoms and medical help-seeking. He stated that it was a doctor that highlighted his risk of prostate disease and of developing PCa and the connections with his urinary changes. This highlights the role of knowledgeable social contacts as a trigger towards help-seeking (Scott et al., 2013). Lee-Ping’s perceptions of low risk were also demonstrated in an international survey that was conducted among the general public and PCa patients across Europe and North America. This survey found that 50% of the participants perceived they were at a low or very low risk of developing PCa before they were diagnosed (Fitzpatrick et al., 2009). A more recent cross-sectional study conducted among men (n=198) aged 18-71 years in the US found that Black men did not perceive themselves at risk for developing PCa (Rice et al., 2017). Lee-Ping experienced a shorter time to medical help-seeking due to the influence of knowledgeable social contacts within his network. Hence, this facilitated help-seeking and subsequently an earlier diagnosis and treatment for Lee-Ping. Disruptive beliefs and emotions are discussed next including self-care practices.

5.2.2.2 Disrupting men’s self-care practices that were influenced by their cultural and religious beliefs

This describes men’s experiences of self-care practices in relation to cultural and religious beliefs and practices towards controlling their debilitating prostate symptoms. Men’s self-practices were disrupted when symptoms progressed. Men’s need for medical intervention was warranted as they could no longer cope with self-management strategies. Men’s first port of call for symptoms experienced were engagement with traditional healers (TH), which differed among ethnic groups; consulting with pharmacy staff and the pharmacist for over the counter drugs (OTC), use of herbalists (herbal use) and the religious teachings of the church. When symptoms persisted, and intensified
men’s normal cultural setting and actions to sort out the problem was disrupted, resulting in actions to contact an HCP. I first discuss Alex account of hesitation in sharing beliefs about TH and herbalist use. I then describe Leo’s interactions with both pharmacy staff and a pharmacist who was a friend of his.

5.2.2.3  Hesitation in sharing beliefs about use of traditional healer and the herbalist

Some men like Alex were hesitant to share about consultations with the traditional healer. Alex later explained that beliefs about the traditional healer were ‘private’ and ‘secretive’.

‘People that live here…in Tobago know about these people. But we don’t really talk about these things. But they know about certain bush and whatnot…and we go for help. I would say that I can be a bit secretive about it…maybe that’s why I didn’t talk about it with you at first. People usually turn up their noses when they know that you’ve been there as though they’re judging you. But these people could help…help the body. It’s a gift they have, and they genuinely do what they do. Well I had tried that, and I felt it worked. He would rub you that sort of thing. My back pains came back after a while. This is what we know here’ (Alex, Tobago).

Alex highlighted the cultural setting of his community in Tobago in relation to consulting with traditional healers, that is, people that shared similar beliefs, perceptions and cultural practices in specific geographical locations in Tobago (Zola, 1966). Alex appeared uncomfortable sharing his interactions with THs during the interview because of his perceptions of being judged. However, Alex’ felt he could safely share this during the interview, but this was not the norm in speaking about these traditional practices. Alex’s perceptions may have been related to the association of TH with witchcraft, which was a common belief among non-traditionalists (Clyne, 2012). Alex believed that traditional healers were knowledgeable and gifted in the area of healing. Fishman describes how ‘dynamic relationships between ancestral heritage can give birth to a specific cultural identity’ as illuminated in the data (1999, p. 3). Alex’ family traditions and practices were contributory to his cultural identity, which were better understood by those belonging to a similar culture or embodied cultural capital because of shared beliefs and values. Embodied cultural capital pertains to knowledge
acquired by individuals over time based on socialization and education within an environment. Cultural capital influences our norms, values and behaviours (Bourdieu, 1986). Alex described his community as a collectivist one, whereby cohesiveness existed among people that shared similar values and belief systems (Carson, 2009; Triandis, 2002). However, Alex’s engagement with THs caused help-seeking, diagnostic and treatment delays for PCa. Leo’s use of pharmacy services as a first point of contact is discussed next.

5.2.2.4 Use of the pharmacy

Some men like Leo reported that they consulted with the pharmacist for stronger pain medication to cope with painful symptoms. For some men, the pharmacist was either a friend or part of their social network. Leo shared that he consulted with his local pharmacist for pain medication to relieve his symptoms of joint pains.

‘I used to ask the pharmacist off and on for any tablet that could help me with the pain because at times I couldn’t even go to work. You know, I’m a tradesman. I work with various businesses and recently it expanded, so I have to keep up. Sometimes the stronger tablets would keep the pain down for a short while but it didn’t last for long so I would just pop in to the pharmacy and get something to keep me up’ (Leo, Trinidad).

Leo’s request for pain medication was sanctioned each time he visited his pharmacist. This contributed to delays in medical help-seeking. Also, Leo’s expanding business served as an incentive to delay help-seeking and self-manage his pains so he could continue his trade. Scott (2013) purports that competing factors, such as work can delay individuals’ help-seeking for symptoms. Leo stated that he ‘had to keep up’, which influenced his decisions to continue taking pain medication so that he could proceed with work. Leo’s use of OTC drugs for his pain and consulting with pharmacy staff and the pharmacist for this impeded medical help-seeking. The role of the pharmacist has been described as the most accessible HCP that serves as first port of call for the general population. However, the pharmacists’ role is noted for self-treatable illnesses (Kehler et al., 2016). Putting parameters in place through limiting the dispensing of drugs by qualified pharmacists was identified in one of the legislations highlighted in TT Ministry of Health as a strategy to promote stricter regulation of OTC drug use (MOH, 2013). Currently, the pharmacist role has evolved and is more patient centred involving the dissemination of drugs and disease information to the general public (Ramrekha et al.,
However, there is no known research in TT that has examined how pharmacists are specifically involved in helping men identify warning signs of prostate disease and cancer. I now discuss Baxter’s self-care practices of using herbs for his symptoms, which contributed to help-seeking delays.

5.2.2.5 Herbal use

Some men held the belief that medical help-seeking should be sought only if self-care had failed. Baxter, a labourer, resorted to self-care because of fears of engaging with the medical profession. He referred to self-care as ‘try my own things’ in the data.

‘I believe that I can use treatment that I know for myself. Yes, the doctors studied. But at the same time, you have to know yourself... what you want. I believe you of yourself can help yourself otherwise. At least try something before running to them. I try my own things. I don’t really go to the doctor unless what I’ve tried has failed. I’ve been sick before and I managed it for myself and it worked. Researcher: In what ways did you manage it? Baxter: All different ways. I’ve used herbs that I boiled and drink for headaches and the cold. Sometimes I wouldn’t take tablets like panadol for any and anything. I would blend different vegetables and drink it. I would feel better. I remember when I had an infection in my urine. I didn’t believe in taking any antibiotics. I just took vitamin C and flushed out the system by drinking plenty water. Sometimes too much medication has side effects and causes more problems in the body. Because when I look out there...long time people used to treat themselves. Some people doctors diagnose, and doctors are not perfect, and they may diagnose cases and might not diagnose correctly, and patients pass away. I know people personally who died at the hands of doctors’ (Baxter Tobago).

The data illuminates Baxter’s discourse of self-reliance towards trying to solve his health problems and not being dependent on others. This was similar to Adam and Ron’s experiences and also links with hegemonic masculine norms. However, Baxter’s beliefs were related to his lack of trust in doctors’ ability to diagnose accurately and links with death as well as the fear of the side-effects of medications on the body. Baxter’s experiences links with two qualitative studies which found that TT men and Black Caribbean people were sceptical to take medical treatment for health problems (Bahall & Legall, 2017; Brown et al., 2007). This could be part of a discourse around natural health and healing. This was also reported by another Trinidad man, Ronald. Baxter gave accounts of persons he knew
that died as a result of medical negligence and his fear of engaging with the medical professionals. As such Baxter uses herbs for his bodily changes. He identified several self-management practices he utilised for prior ailments such as the common cold, urinary tract infection and headaches. There is evidence, which shows that self-management increases the time taken to seek medical help in the pathway to diagnosis (Mesfin et al. 2009), which occurs most frequently among men from lower socioeconomic level (Winterich et al., 2009) as seen with Baxter who worked as a labourer. However, self-management occurred equally among men of both lower and higher socioeconomic status among men in the study. Self-management lengthened the time to help-seeking for most of the men in the study. I now discuss the influence of religious beliefs in lengthening time to seek medical help for Cameroon.

5.2.2.6 Religious teachings and beliefs

Cameroon’s experiences of disruption pertained to his beliefs that his symptoms were connected to demons. He stated that the information he received about PCa disrupted his religious convictions developed from his church teachings in relation to his belief that demons were responsible for ill health.

‘I had to put aside my beliefs because I wanted to see a doctor. We are Christians but not of the same denomination. I no longer believe in that demon thing. I feel once you are ill the doctors are there for that reason and I am happy I went in the doctor said the earlier you come in you have a better chance of being treated for this. I believe in prayer and all that but not the way my wife believes. I never really explored that realm of spirituality. I know that there is evil out there, but I believe in the goodness of everything. And if you are a good person you could fight off evil. That’s what I believe’ (Cameroon, Tobago).

Cameroon experienced a conflict between his personal and family beliefs about his bodily changes as connected to demons and seeking medical help. This was evidenced when Cameroon said, ‘I had to put aside my beliefs’. Initially this belief delayed Cameroon’s help-seeking actions. Knowledge gained about PCa facilitated help-seeking for Cameroon. He stated that he no longer held his former beliefs, as he is now aware of the significance of an early diagnosis and early treatment for prostate disease. Similar to Cameroon, some religious beliefs have been seen as a deterrent to PCa screening for men. These were related to fatalistic beliefs that PCa was a punishment from God (Blocker et al., 2006). Also, the influence of evil stated as the ‘evil eye’ was another belief among Latinos that this
contributed to PCa development. These religious beliefs delayed medical help-seeking for these individuals (Allen et al., 2014). Colin’s disruptions of his emotions are discussed next.

5.2.2.7 Disrupting emotions

Colin, a 47-year-old carpenter described turning ‘a blind eye’ towards his urinary changes, severe pain and weakness because of the spiritual distress experienced. He was angry that these bodily changes occurred to him, which he connected to being ill and needing medical attention.

‘I didn’t do anything about it initially. I was angry. I questioned why this had to happen to me. My urine used to sort of drip, and I had some back pains for a while. I knew I had to go to the hospital, but I travel to the US quite frequently. I was struggling financially you know. As soon as things picked up, I got a job, I was happy, suddenly all this came upon me. I turned a blind eye to this. But it only got worse and I went in here at the hospital and also in the US. Well I can’t travel anymore. I’m bound for here’ (Colin, Trinidad).

Colin’s perceptions of meanings related to his bodily changes triggered perceptions of a disruption to certain life events such as future travels, happiness and his work. Bury (1982) explains how individuals like Colin search for meanings to their bodily changes in context of disease causation when their normal biography is disrupted. Questions such as ‘why me? why now?’ are normal during this experience. These questions also point to signs of spiritual distress (Aghadiuno, 2010). Colin’s anger caused him to delay going to the doctor even when he perceived his symptoms as needing medical attention. He questioned why he had to experience these debilitating symptoms when he was happy and had recently obtained employment. Colin’s reaction to his disruption was turning a blind eye to his symptoms in order to enjoy what he had accomplished. Colin’s interpretations of his symptoms were ‘a doom and gloom’ evidenced as ‘I can’t travel anymore. I’m bound for here’. Participants in one study conducted in the USA also shared Colin’s beliefs about cancer. They equated cancer with a death sentence and avoided doctors when they experienced symptoms suggestive of cancer, such as back pains and blood in urine. As such, this delayed help-seeking (Moser et al., 2014). I now discuss men and partners’ experiences of disruptions in their relationships.
5.2.2.8 Men and partners’ accounts of disruptions experienced in their relationships

This highlights the experiences of disruptions in relationships. It was important to look at this from the perspective of both men and their partners to examine the ways in which they were affected along care pathways. Isolation in relation to concealment of symptoms and its link with the masculine image were elucidated from Clement’s and Petra’s perspective. Clement described how he isolated himself from his partner to cope with his disruptive symptoms. Petra explained how her husband’s isolation put a strain on their marriage. Roland hid his distressing health concerns from his wife so as not to cause further upset to her ill health and Ria shared how her husband denied his symptoms although they were disruptive for him.

Clement explained that his urinary symptoms experienced initially were taken for granted. However, when these symptoms persisted, he felt that this was a sign of poor health. He stated that he chose not to discuss this with his wife. These contributed to a period of physical and emotional isolation.

‘I would be at work doing buildings and I would want to pee, but it would be painful. I didn’t think it was anything serious at first. A lot of thoughts started to go through my mind, you know. At that time my wife and I were not on speaking terms. She realized something was wrong because I just wasn’t there…I was at home, but I wasn’t really talking or anything. Normally we do everything together, so she was concerned that something was wrong. I had to be alone for a while. So, I used to go out late, work a lot just to be alone for a while to deal with this’ (Clement, Tobago).

Clement isolated himself from his wife in order to cope with the changes in his body. Feelings of embarrassment may have been Clement’s reason for not sharing these with his wife. Charmaz (1983) highlights that social isolation is one of the ways men deal with the threat of symptoms on their masculine image. Clement’s isolation may have been related to worries about his sexuality and identity as a man, in relation to the disruptive effects of his symptoms and his perceptions of these. Concealing vulnerability and fears are connected to hegemonic masculinity. These relate to social norms that men should be resilient and hide emotions of fear and worry (Connell, 2005). In the data, Clement utilised a period of isolation to protect his masculine image and cope with his symptoms and fears surrounding these. Clement’s actions with regard to isolation may have been influenced by his current relationship with his wife. He stated that they were not communicating at that time. This may
have contributed to his decision to be reticent about his bodily changes. Radley (1994) highlights that social withdrawal may occur among individuals during the symptom experience as demonstrated with Clement. This he posits is one mode of adjustment to illness (Radley, 1994). Men were also found to isolate themselves from their wives as a coping mechanism in a study that looked at couples’ experiences of PCa (Gray et al., 2000b). Petra’s accounts of how her marital relationship was disrupted are discussed next.

Petra stated that her husband, Frank travelled to the UK unknowingly to her in order to conceal his debilitating symptoms. She became aware of this when Frank was admitted to the emergency department and was hospitalized. Petra shared that her husband’s decision to travel put a strain on their marriage.

‘He didn’t tell me anything. I found it strange when Frank said he had to travel to the UK. But I didn’t realize that he had planned on going there to hide his pains from me. It affected our relationship because I was wondering what’s going on. He just left work and after a few months or so he came back and that was when he told me the truth that he was battling with pain and other problems. I was hurt that Frank didn’t tell me about this earlier on. I couldn’t understand why. I mean I’m his wife and I didn’t know. When he came back, he said he needed space to understand exactly what was happening to him and how to make sense of it’ (Petra, Trinidad).

Petra described how Frank’s silence about his progressively worsening bodily changes and subsequent isolation disrupted their relationship. She desired for Frank to be honest in sharing his health concerns with her. Bury (1982) highlights that hiding symptoms from the family is common for individuals in recognising their symptoms as an illness. This isolation for Frank was instrumental towards separating his disease from his selfhood and transitioning to a need to seek help. This concerns the perceived loss of a healthy body and time taken to come to terms with what was happening and then making decisions about whom to disclose these bodily changes with. Frank’s period of isolation resulted in help-seeking and subsequently diagnostic and treatment delays for PCa. Concealing symptoms were common among men from Tobago. However, for Roland this was done to protect his wife from further distress as discussed below.
Roland remained silent about his health problems due to sensitivity to his wife’s health condition. He perceived that disclosure would cause emotional upset and additional burden in her illness.

‘My wife had a stroke and she is still recovering. She is eighty percent there, so I don’t want to add to her burdens. I want her to get better. So, if I’m not feeling well, I wouldn’t let her know. She’s already low and I don’t want her to start worrying about me. Before the stroke she was always supportive and would attend to food and take care of the meals and whatnot’ (Roland, Trinidad).

Roland stated that his wife was recovering from a stroke. He perceived that disclosing his health problems to her would cause worry and contribute to further ill health. Roland decided to conceal his symptoms due to these reasons. A few other men from Trinidad shared that they did not disclose health concerns with their wives. Hegemonic masculinity norms were a major theme arising from findings related to non-disclosure of ill health. Reasons such as, ‘my wife had travelled’ and ‘we were no longer in a relationship’ were given. However, it was noted that most men from Trinidad informed their wives/partners about their symptoms. I now discuss Ria’s accounts of her husband’s silence and her reciprocal silence.

Ria shared how her husband Matt would normally not complain about headaches or back pains until she noticed this and confronted him about it. She believed that ‘silence’ in reporting symptoms were cultural in nature.

‘Times are slowly changing but I could remember when I was a teenager, I wouldn’t tell any of my classmates or my teacher if I was getting period pains. I would just cry in a corner…it was private for me. Not only that...with headaches or even the flu. I don’t know what it is. It could be our culture. I notice that most people here don’t like talking about sickness. For instance, my husband was getting back pains years ago and he didn’t even say anything. When I asked him what’s wrong...he would say nothing. Eventually he had to be hospitalized for the same
problem. Men here feel that women should know their place. They don’t like you as a woman to question them...so I don’t. But knowing the culture where people don’t like to talk about these things. It’s as if we feel evil will prevail and you will get worse. Not for me anymore. I talking freely about these things. Sometimes talking about it helps to ease stress. You could get advice from people as well and you have to tell the doctor. How he would know what’s wrong with you?’ (Ria, Tobago).

Ria described her husband’s silence about his symptoms. This links with fear of attending health services and possible connections with a serious condition and contributes to help-seeking delays, like Matt (Taber et al., 2015). Ria’s reported partners’ account of silence may have also related to him not wanting to attend health services due to his stoic masculine image and protection of his vulnerability (Connell, 2005). There is also a belief that talking about health matters worsens it. A recent meta synthesis found links between perceptions of cancer as a death sentence and fear of cancer proximity (Vrinten et al., 2016), as seen with Matt. His experiences of fear of cancer and attending health services contributed to help-seeking delays. Whilst some men delayed consulting about symptoms suggestive of a serious health problem, other men like Matt perceived that symptoms were connected to another condition: diabetes mellitus, which significantly delayed appraisal of symptoms and help-seeking actions. This is discussed next.

5.2.2.9 The belief that diabetes was the cause of disruptive symptoms

Some of the men who were diabetics reasoned that their bodily changes of urinary dribbling, decreased urine flow and erectile dysfunction were related to this condition. This led to normalization, which delayed appraisal and help-seeking. Cain reported this as, ‘I felt these were connected to my sugar’. His thoughts relating to his interpretation are described below:

‘I’m diabetic and the first thing I noticed is that you can’t hold your pee or anything like that. If I intend to go and pee and I ain’t able to get ready to pee, sometimes you know it might drip out and when you’re peeing it not like forceful like from before when you peeing it does shoot out, you know. Also, for some months now I have erectile dysfunction. I felt these were connected somehow with my sugar or something like that, but I didn’t know how to make sense of it, so I didn’t tell my doctor about it (erectile dysfunction). But it ain’t really bothering
Cain connected his urinary symptom experiences with normal pathology related to diabetes mellitus. He described his bodily changes as ‘not bothering’ him and as such interpreted these as not serious. This could have been connected to embarrassment of discussing these changes with his doctor as this was part of his manhood and masculine image. Cain highlighted that he did not pass blood in his urine nor experienced pain. For Cain, blood in the urine and pain would legitimize a need to see an HCP. And since he had not experienced any of these, he accepted them as being part of his diabetes condition. Researchers have shown that individuals may misattribute urinary symptoms of prostate disease for symptoms of diabetes mellitus because of the similar disease-pattern, as experienced by Cain and other men in the study (Mobley et al., 2015). Some of these symptoms that are similar to those associated with diabetes are nocturia, fatigue, sexual changes and weight loss. Bury (1982) postulates that the processes of recognition and legitimating an illness are problematic especially when symptoms coincide. It is quite common for misinterpretation to be experienced among men with a lack of knowledge of prostate symptoms, like Cain, which has been found to affect individuals’ appraisal of cancer, delay help-seeking and lengthen the appraisal interval (Corner et al., 2006; Smith et al., 2005; Turris & Finamore, 2008).

5.3 Summary of ‘Disrupting the self’

Disrupting the self was discussed in relation to asymptomatic and symptomatic men’s experiences. This links with Bury’s (1982) biographical framework of biographical disruptions that men experienced physically, emotionally and socially. Social and emotional disruptions were experienced by asymptomatic men in response to provider silence. This contributed to men’s withdrawal from clinical trials causing men to sever relationships with HCPs. This subsequently delayed help-seeking and diagnosis of PCa as men had to recommence their prostate care at other health services. Men’s perceptions of the benefits of external health locus of control led to emotional upset when men presented with symptoms suggestive of advanced prostate disease. Economical, physical and social disruptions were experienced by symptomatic men. These were connected to disruptive effects of symptoms on men’s role as breadwinner of the family. It also represented the physical burden of bodily changes and effects on marital relationships as evidenced by men’s withdrawal, isolation and hiding symptoms.
Stoicism set a higher threshold for help-seeking for men with African ancestry and one man of Chinese ethnicity perceived he was exempted from developing PCA. These perceptions extended the time taken to consult a doctor for symptoms suggestive of prostate disease. Disruptions of men’s normal biography also occurred in relation to failed self-care practices, such as the use of herbs and OTC through pharmacy staff and religious teachings. These also contributed to help-seeking delays. This resulted in emergency admissions (discussed further in the next chapter). And men’s perceptions of the connection of urinary symptoms and diabetes significantly delayed appraisal of bodily changes and help-seeking actions due to these misattributions and misinterpretations. The proceeding chapter pertains to men and partners’ diagnosis and post diagnosis experiences. It describes their accounts of the two-fold silence that contributed to ‘The Silent Wall’ during diagnosis. This represents their perspectives of HCPs silence, highlighted by the category, ‘Nobody told me’ and the men’s reciprocal silence elucidated as ‘I didn’t ask’.
CHAPTER SIX – FINDINGS: MEN’S DIAGNOSIS AND POST-DIAGNOSIS EXPERIENCE OF PCA IN TT

6.1 Introduction

In the last chapter I discussed men’s pre-diagnosis experiences for PCa in TT. I highlighted asymptomatic and symptomatic men’s initial experiences, which were represented by the category ‘Disrupting the self’. This demonstrated how provider silence caused men within clinical trials to disrupt their prostate health care leading to help-seeking delays. For symptomatic men, I illuminated how hegemonic masculinity norms and beliefs systems influenced men’s reluctance to seek help for their prostate symptoms in a timely manner until these disrupted their physical threshold, ability to work and provide for their families and relationships. Men’s reluctance to seek medical help and bearing symptoms until these were advanced contributed to appraisal and help-seeking delays, and subsequently diagnostic and treatment delays.

In this chapter I discuss men’s diagnosis and post-diagnosis experiences. This part of the journey is represented by the categories, ‘Disconnected to health services’, ‘The silent wall’, ‘Blame and distrust’ and ‘Silent breakers’. Disconnected to health services shows how men’s first contact with health services was done through emergency admission. It also highlights factors that led to help-seeking and diagnostic delays. ‘The silent wall’ identifies silences experienced along routes to diagnosis that resulted in a breakdown of communication between men and HCPs. Blame and distrust portrays men’s attribution of accountability for their diagnosis of advanced PCa. And lastly, ‘Silent breakers’ depicts how the role of knowledgeable social contacts, questioning and requesting information, and publicising prostate screening contributed to smoothening men’s journey along routes to diagnosis.

6.2 Disconnected to health services

This category emphasizes factors that contributed to men’s help-seeking, diagnostic and treatment delays. Men’s first contact with public health systems were at emergency health services when they presented with debilitating symptoms such as urinary retention, bone and back pains. Men’s non-
adherence to safety netting contributed to diagnostic and treatment delays. Disconnected to health services also identifies reported scheduling delays, long waiting times, shortages of skilled staff, referral, diagnostic and treatment delays for PCa. I discuss ‘Disconnected to health services’ under the headings ‘Men’s late presentation at emergency health services’ and ‘Feelings of disconnectedness to health services’.

6.2.1 Men’s late presentation at emergency health services

Most of the men in the study including those that indicated their involvement in prostate clinical trials presented to emergency health services with symptoms suggestive of advancing prostate disease. Mark stated that he was admitted for emergency prostatectomy after leaving the clinical trial. And Ron describes his experiences of presenting to the emergency department with urinary retention.

Mark stated that after leaving the clinical trial he had an emergency radical prostatectomy.

‘It got worst… the toilet bowl was full of blood and I was feeling tired… no energy. I went to the hospital and the doctor said I would have to remove the prostate. He said the prostate was enlarged so it was causing urine to back up in the kidneys and that I would have to remove the prostate, and that prostate would be solved. So, I had it removed and they test it and it wasn’t cancerous then’ (Mark, Tobago).

Mark explained that his health situation worsened after leaving the clinical trial. He described symptoms of haematuria, fatigue and an enlarged prostate, which led to a medical decision to perform a radical prostatectomy at the public health system. Mark’s severance from the clinical trial contributed to diagnostic and treatment delays. Continued provider silence at the public health system further contributed to ‘Blame and distrust’ when Mark later found out that his prostate was not removed during the surgery. This is discussed in 6.4.3.

Ronny a 65-year-old joiner described his experiences of late presentation at emergency services for urinary retention. He explained that after he was catheterized, he did not adhere to safety-netting as advised by one doctor at the emergency department.
'The urine slow down and then I couldn’t pee. I had to go to emergency because I was in extreme pain. If I had gone when I noticed I couldn’t pee it would not have been so painful to drive. I felt I could handle it. I didn’t stay long. They pass a catheter and I went home. They told me to go to the clinic. I didn’t go back (hospital) until the same thing happened to me again’ (Ronny, Trinidad).

Ronny experienced decreased urine flow and was later admitted to emergency health services for urinary retention. McPhail et al (2013) found that individuals presenting in emergency demonstrated shorter waiting times, like Ron but higher mortality rates and poorer outcomes. This was found across all cancer types. Ron did not adhere to the referral to urology clinic. Scott et al., (2013) highlights the importance of safety netting that usually occurs during the diagnosis interval. Safety netting is referred to as a critical component of primary care consultation and is important for suspected cancer. It is a diagnostic strategy that is utilised by HCPs to keep patients within the health system through follow-up care (Neighbour, 2004). Ron stated that he did not attend health services until he experienced another episode of urinary retention. This break in safety netting led to delays in help-seeking and subsequently prolonged Ron’s diagnosis and treatment.

6.2.2 Feelings of disconnectedness to health services

This describes men’s accounts of a lack of engagement with HCPs and silence about their test results, diagnosis and treatment, which was due to shortage of staff and in turn long waiting times to be seen, scheduling delays and system failures such as malfunctioning diagnostic equipment. Clement experienced delays in obtaining his PSA blood test results due to shortage of laboratory staff. Luke’s delays in receiving a prostate biopsy were reported by him as a lack of skilled doctors.

Clement is a 54-year-old farmer and a hypertension patient. He explained that a blood sample was drawn at a local health centre for a PSA test after a routine prostate examination (DRE) showed enlargement. He experienced delays in receiving his PSA test results due to shortage of laboratory staff.
‘Well I used to go by the health centre in Mason Hall to check my pressure. They took a look at it (DRE). They told me the prostate was a little large. I didn’t know they use to check other things. They said they would do a blood test before they send me to the hospital. They took a blood test (PSA). That was my first bad experience. When they took my blood test, my blood was too thick, so they did not get to take my test, and you know they have me waiting. And, you know how it is, they tell me to come back in 3 months’ time. And when you sit down 3 months, hoping that when you go back you will get the results of the test. When I go back, I am hearing that the blood was too thick, so they couldn’t even do the test. I feel so bad about that. That is not good enough! They could have called me to tell me that the blood was too thick. I decided to go privately because of that experience’ (Clement, Tobago).

The data excerpt above reflects the prolonged waiting time Clement experienced in receiving his PSA test results. This caused Clement to feel disconnected to the health services as he was uncertain about his PSA results and desired to get a diagnosis for his symptoms. Due to Clement’s experiences of delays at the public health system he made a decision to go to the private health system to overcome these. Scott (2013) highlights that certain processes within the diagnostic interval can contribute to diagnostic delays, such as the availability of health care system, as seen with Clement. A routine DRE showed that Clement had an enlarged prostate. However, due to shortage of laboratory staff Clement’s diagnostic interval was lengthened by six months. This subsequently led to treatment delays for Clement. Coagulated blood samples are common in medical practice (Upreti et al. 2013). One UK study showed that 80% of health systems had no fail-safe system to ensure laboratory results had been returned to health practices. Patients were only aware that results were delayed only when they requested these (Litchfield et al., 2015). This was similar to Clement’s experience.

Similarly, Luke experienced diagnostic delays with regard to his prostate biopsy examination. However, unlike Clement who experienced delays in receiving his PSA test results due to a shortage of laboratory staff and lack of a fail-safe system, Luke’s diagnostic delays were with regards to a shortage of skilled doctors. Luke, a 58-year-old retired police inspector was diagnosed with stage 11 PCA and was referred to the diagnostic department at the public hospital to get a prostate biopsy. He stated that a lack of specialist staff in Tobago contributed to referral and diagnostic delays and long waiting times to be seen.
‘And then the doctor tell me he will refer me to the urologist, but the urologist comes from Trinidad and its about 3 weeks he didn’t come. So, because of that I only got to see him about 3 months after that. He sent me to do a biopsy. He told me the biopsy machine was not working at the hospital so he told me I will have to hold on. It took about 5 months to call me. I could remember the exact date because when they call me it was the Monday after the jazz festival. He tell me to come up here for 8 o’clock. I sat down here till 1.30-2’0 clock and nothing happening. Well people who were there started making noise. Well I did not make any noise, I just tell myself when I see 2’0 clock I will go. It had about 10 of us and you know I think I was the youngest among them and you know they tell you not to eat anything, not even water and you know you’re feeling hungry and all these things. So, after the doctor came and he apologized. He said its only 2 doctors that could do it, but they also work in surgery and they could not come until surgery finished. He said and it was only he alone and he would start around 2 o’clock. I was the second person that went in (for the prostate biopsy procedure) and I noticed that while he (health care provider) was doing it I started feeling sick like if I want to sleep. So, I ask the nurse if they gave me anything to put me to sleep and she tell me no. I couldn’t even come off the table and she had to help me. She tell me to sit down there and wait about 2 hours because the doctor had to talk to us. Afterwards I still feeling weak. I found out after (from one doctor at another hospital) is that usually they give you antibiotics and they tell you to buy something like that and take it before you come in for the biopsy in case you get any infection. But they didn’t tell me that I had to take the antibiotics before getting the procedure’ (Luke, Tobago).

In the excerpt Luke stated that it took three months to see a urologist. This identified referral delays that occurred within the Tobago public health system. Luke also experienced systemic and scheduling delays in obtaining an appointment for the biopsy procedure because of a malfunctioning machine. Luke’s excerpt highlighted a shortage of skilled staff at the hospital when he attended for the biopsy procedure, which affected the waiting times. Significantly prolonged wait times for a cancer diagnosis have been linked to poorer prognosis and death among men with PCa (Stevens et al., 2010). However, Luke was diagnosed with Stage II PCa due to his knowledge of PCa and movement to private health systems. This facilitated timely diagnosis and treatment for Luke. Additionally, shortage of staff, high
patient workload and burnout also contributed to missing Luke’s antibiotic administration pre-biopsy procedure. This resulted in Luke’s development of a life-threatening infection, for which he was hospitalized for a few weeks.

6.2.3 Summary of ‘Disconnected to health services’

Disconnected to health services was discussed as it pertains to men’s late presentation and emergency admission and feelings of disconnectedness due to shortage of staff and provider silence experienced. This category also identified how men’s late help-seeking behaviours and their lack of safety netting contributed to diagnostic and treatment delays. Men’s experiences of long waiting times to be seen by doctors inclusive of scheduling delays and system delays also resulted in diagnostic and treatment delays. The next category, ‘The silent wall’ in which men reported a reciprocal silence in response to provider silence is discussed next.

6.3 The silent wall

The silent wall along routes to diagnosis further compounded men and their partners’ experiences in the midst of the shortage of staff and increased workload. Participants were not invited to ask questions as HCPs tried to manage the clinic to be speedy and did not want to be hindered by questions from patients. Men’s accounts of HCPs silence were highlighted with Clement and Luke regarding test results and antibiotics administration respectively. Some men also explained that they were reticent and did not question nor ask HCPs about their situation whilst engaging with health services. This was due to their reciprocal silence, seen in the data as silence in response to HCPs silence along routes to diagnosis for PCa. Factors underlying men’s silence were a lack of self-confidence due to lack of education as experienced with Adam and not receiving an invitation to ask questions from his doctor as seen with Paul. Leo’s perceptions of power inequalities contributed to his silence and Greg remained silent because of hegemonic masculinity norms.

6.3.1 Silence due to lack of self-confidence

Adam reflected on his reciprocal silence that was experienced in consultation with his providers when he identified the lack of communication from his providers regarding his diagnostic test results and
meanings related to these. He perceived himself as a ‘normal man’ in relation to HCPs because of his perceptions of doctors as authoritative figures, which silenced him with regards to questioning his doctor.

‘The doctors would focus on writing but wouldn’t talk much. Nobody told me anything about my PSA. I never really asked any questions even though there were things I wanted to know about. Who am I? I am just a normal man on the streets. I never went to school...not high in society. That’s the way it is’ (Adam, Tobago).

Adam’s perceptions of himself influenced his silence. He demonstrated hierarchal positioning through his feelings of inferiority and his perceptions of himself being of a lower status than his doctor. This was evidenced when he stated, ‘who am I?’ and described himself as ‘normal’ and ‘not high in society’, in comparison to doctors. This type of silence Adam experienced is known as diffident silence, which is associated with a lack of self-confidence as postulated by Brinsfield (2013). This occurs among individuals of a lower socioeconomic status like Adam who had not been to school that is usually developed because of insecurities, self-doubt and uncertainty which influences the ability to speak up about concerns or ask questions (Brinsfield, 2013). Adam’s perceptions of being uneducated placed him on a different level with his doctor, which silenced him and revealed his vulnerability. Since Adam had not been to school he depended on his doctor’s expertise and knowledge towards his health concerns. Similarly, Greenhalgh et al (2015) posited that power inequalities in healthcare significantly suppressed patients’ voice, which caused further vulnerability in ill patients and disempowerment. Similar to Adam, researchers found that HCPs had a better rapport with patients of similar social class and provided them with more information in comparison with patients from a lower social class (Banerjee & Sanyal, 2012).

6.3.2 Silence due to lack of invitation for asking questions

Paul is a 56-year-old farmer who experienced painful urination, blood in the urine and back pain. At one consultation with a private doctor he was told that he had a spot on his prostate, which triggered questions about meanings related to this. However, he did not question his doctor.

‘I wanted to know what he meant by a spot on my prostate, but I never asked. And he never asked me if I had questions as well. That pushed me to go privately. Money talks. I heard that
doctors are better there. But thinking about it now I should have asked and not wait on that doctor’ (Paul, Tobago).

Unlike Adam, whose silence was in relation to his lack of self-confidence towards seeking answers for his health concerns, Paul’s silence was in relation to not receiving an invitation for questioning. This was exemplified in the excerpt as, ‘he never asked me if I had questions’. Paul felt very subordinate to his doctor like a waiter rather than a client. This influenced Paul’s decision to go to a private health system. He described unmet expectations of the HCPs’ roles towards providing an opportunity to ask questions. Murtagh et al., (2013) highlighted HCPs critical role towards engagement during consultation by assessing for cues and information needs and providing opportunities for patients to ask questions, which Paul desired. He reflected on his experiences and felt that he should have asked questions and not wait on his doctor. Paul’s and other men in this study experiences may have been related to their perceived power relationships and etiquette in consultation of not questioning the expert, according to sociologists. They purported that doctors were perceived as God in relation to their patients and as such were not supposed to be questioned (West, 1984). Paul’s experiences contributed to perceptions of the public system as uncaring because of free healthcare versus the private system as efficient and superior because of the cost attached to services rendered. This was evidenced when Paul stated, ‘money talks’ and ‘I heard that doctors are better there’. Other men in this study and in the literature shared Pauls’ perceptions. It has been found that lower quality of care existed in the public versus private health system among GPs that worked in dual health systems. One major reason identified was that private health system served mainly persons from the upper class, which enabled higher profits to be gained through insurance. This was economically favourable for doctors, which facilitated better work performance (Brekke et al., 2007).

6.3.3 White-coat silence

Leo, a 62-year-old private business owner reflected on his experiences while attending at a private health facility for changes in his urinary pattern. At that time, he had a prostate biopsy done which was non-cancerous. Leo explained that he had questions he wanted to ask but remained silent when his doctor advised to ‘wait and see’. Leo emphasized that he failed to ask questions because of his perceptions of power imbalances in the doctor-patient relationship.
‘When I had the first (prostate) biopsy, the doctor said it’s not cancerous, let’s wait and see, which led to a year. I am not in the medical field to know what it is, so I didn’t ask. I would have asked him why wait for so long? But you know they are doctors, why question them?’ (Leo, Trinidad).

Leo’s silence is highlighted as ‘white-coat’ silence in the medical literature. This is a phenomenon that occurs in consultation with doctors in which patients avoid asking questions because of fear of being labelled difficult or wasting the doctors time (Judson et al., 2013). Leo referred to doctors as ‘they’ and ‘them’ and highlighted that he was not in the medical field in the excerpt above. He viewed doctors as ‘high powered’ and ‘knowledgeable’ because of their expertise, which he believed should not be questioned, even in the midst of uncertainty. Interestingly, Joseph-Williams et al., (2014) study on perceived power-imbalances within healthcare found that patients defer to doctors due to their expert knowledge. This affected knowledge provision, knowledge acquisition and expectations. This was similar to Leo’s experiences. He did not understand the significance of participating in consultations by voicing his personal preferences. He accepted the ‘wait and see’ management for his prostate problems without addressing his concerns, which hindered shared decision-making. Leo’s management may have been ‘watchful waiting’. A recent TT review paper has identified the challenges and pitfalls associated with Active Surveillance (AS) in Afro Caribbean men. Although AS can reduce overtreatment it remains controversial as a treatment for Black men due to their higher risk of developing aggressive types of PCas and poorer outcomes (Persuad et al., 2017).

6.3.4 Silence due to masculinity

Greg reflected on his contributory silence in consultation with his provider when his HCP told him that his PSA was high and that his biopsy was ‘suspicious’. Greg stated that he wanted more information concerning these but did not request any additional information to clarify his misconceptions because of his perceptions of masculinity in consultation.
‘Well, my doctor told me that my biopsy was suspicious, but he didn’t explain further what it meant, and he still hasn’t said anything about my PSA. I would wait on him to tell me. As its prostate, I wouldn’t involve my wife in this. Women talk as twice as much as men. She would ask questions. Women are more talkative. I would spend 5 minutes; she would take half an hour. We keep things short’ (Greg, Tobago).

Greg’s demonstrated hegemonic masculinity was related to avoidance of long consultations. He preferred to wait on his doctor to provide him with further information at another consultation. Hegemonic masculinity was further exhibited when he spoke about his wife and emphasized how women spend more time in consultations because they would talk more and ask questions, in comparison to men who would ‘keep things short’. Also, not wanting his wife to accompany him to his appointments was influenced by his perceptions that she would lengthen the time by asking questions. Additionally, he viewed his prostate problem as a man’s issue. Greg highlighted the issue of time, which may be due to prior experiences of interacting with doctors and his perceptions of normality regarding consultations. ‘Perceptions of wasting doctors’ time’ were highlighted in a recent study due to hastened consultations, some of which were reported silence, lack of rapport and sensitivity to concerns (Llanwarne et al., 2017). The data excerpt also highlights Greg’s respect towards his doctor, which led him to wait for concerns to be addressed rather than question him.

6.3.5 Summary of the wall of silence

The wall of silence elucidated men’s accounts of silence in response to provider silence that was experienced due to shortage of staff, busy clinics, malfunctioning diagnostic equipment and increased doctor-patient work load along routes to diagnosis for PCa. Several factors such as lack of self-confidence, perceptions of power imbalance in provider-patient relationships, not being provided with an invitation to ask questions and hegemonic masculinity norms, accounted for men’s reciprocal silence. The category of ‘Blame and distrust’ is examined next. This describes men’s experiences after they were diagnosed with PCa.
6.4 Blame and distrust’

The category ‘Blame and distrust’ pertains to men’s accounts of a diagnosis of PCa and problems encountered that led to significant delays. Most of the symptomatic men that delayed medical help-seeking attributed blame to themselves. Very few men experienced shared blame in which they held themselves and HCPs accountable. This was inclusive of the Government’s role in advertising PCa. These are discussed under the headings ‘self-blame’, ‘shared blame’ and ‘casting blame.

6.4.1 Self-blame

Some men attributed blame to themselves. These were mainly related to former lifestyle practices such as alcohol consumption, eating of red meat and having more than one sexual partner. Janoff-Bulman (1978) purported two types of self-blame: behavioural and characterological. Behavioural self-blame relates to modifiable control and has been associated with individual’s belief of avoiding future negative outcomes, whereas characterological self-blame stems from non-modifiable control that pertains to individuals’ character. Men in the study experienced the two forms of self-blame. For example, with behavioural self-blame even though men in this study could not change their diagnosis of cancer, they described the importance of encouraging men to attend early PCa screening clinics for the digital rectal exams, like Matt. This is discussed under the category, ‘Breaking the silence’. For other men, self-blame was related to lifestyle habits and involved a change in self-esteem, such as eating unhealthily and alcohol consumption, as seen with Matt and Jason, and concerns about having multiple sexual partners, as expressed by Pete and Clement.

Matt and Jason explained that their lifestyle habits contributed to the development of PCa. Matt reflected on his large consumption of cheese and meat as a child. He believed that these two reasons were significant to his PCa progression. Matt explained that illnesses and diseases resulted from man’s own doing.

‘I believe that God set everything in motion. We have everything needed you see. The only thing that man does really suffer for is man-made thing. You know oxygen, sunlight, strength you know all them thing is God given. But what we eat is our responsibility. I eat a lot of cheese. In fact, I could remember eating large amounts of cheese and meat too as a child. And I developed a love for this throughout my adult life. I think PCa and other diseases are all man’s
own doing. We cause these things to happen to us by what we eat. I know I have it, but I say my prayers and read my bible. I meditate on God a lot too. I warn men from work and who I know to get tested and eat a healthy diet with more vegetables and less meat’ (Matt, Tobago).

Matt believed that man and not God was responsible for sicknesses and diseases. He explored a connection with his eating patterns of cheese and meat from as early as a child and his development of PCa. Theorists have examined the effects of self-blame as being two-fold, that is either debilitating or strengthening to psychological adjustments (Janoff-Bulman, 1979; Abramson et al., 1978). Both forms of self-blame can promote self-growth, and a strengthened character (Janoff-Bulman, 1979), as experienced by Matt who described being on a personal level with God. In addition, he has encouraged men to get tested for PCa.

Jason believed that his beer drinking contributed to cancer development. He stated that he consumed a large quantity of beers at the time when he first developed difficulty urinating.

‘Miss, I believed it is the Carib (beer) that caused this (PCa) to happen (develop). Yes, because I was good...good all the time. I had no problems at all is that Carib that caused that. The whole day I was drinking from 2 o clock to about 8 or 9 o clock the night. I usually drink Carib. And people that I know said they believed is my drinking caused it. But looking back now at all the beers I drink. Hmmm...I feel bad... I feel I cause the cancer to come about’ (Jason, Tobago).

Jason believed that there was a connection with PCa and beer drinking. Sontag (1978) illuminated self-blame and its relationship to perceptions of ‘bad living’, which are caused by stigmatization of cancer, as exemplified with Jason. He believed that his ‘bad lifestyle’ caused his PCa, which was also supported by people he knew. Jason expressed guilt about his beer drinking lifestyle. Guilt and self-blame have been postulated by theorists to be rooted in anxiety (Sontag, 1978; Greenwald, 1992) as exemplified with Jason.

Clement stated that he was asked about his sexual history by one of the nurses at his initial assessment meeting at a prostate clinic. Upon being diagnosed with PCa, he perceived that his sexual history of having more than one partner caused him to develop this disease. He blamed himself for developing PCa because of this information and his beliefs as he shared in the interview.
'I remember they had asked me at the prostate clinic if I used to sleep around and I was honest. I used to have other women besides my wife. You know some men are more hot-blooded than others. So, I would have sex with another woman and still sleep with my wife. I think that put force on the gland, so maybe that is what caused it. Stress and women. Those two things I feel caused the PCa. Those are my personal beliefs. I ask the Master to help me to cut off the ladies at a certain age. But you know the devil would put these ladies in your way. So now I cut off – and I feel good about it. We always there for one another. We discuss everything, we travel together. I am a family man – I believe in family. I always do everything in my home. I don’t give her a chance to say that I am not doing anything in the house. Because my wife – she is not a hot-blooded person, you know some men might like sex more than some. And some men, if they can’t get the sex from their wife – they feel they have to go outside to get it. In the earlies I used to quarrel with she – and say you are so cold blooded, like you don’t like to have sex. I would quarrel, and I would go and find a lady outside. But now when I realize I can’t do anything – and she is a very humble and understanding lady – I take back all those things that I told her. I sorry I tell she these things – because if she was a hot-blooded person that I wanted her to be.... hmmm.... what would happen. Understand? Life is a funny thing. Thank God she is an understanding lady’ (Clement, Tobago).

Clement believed that his sexual lifestyle and physical stress caused him to develop PCa. He perceived that this put pressure on the prostate gland causing cancer to develop. Other men in the study also shared this belief. Clement stated that he had asked the Master to help him towards dissolving extra marital relationships but that the devil kept putting women in his way. His diagnosis of PCa influenced his decision to sever ties with other women and he is now faithful to his wife. Clement’s experiences influenced his external locus of control (Rotter, 1966). He shared that he is now thankful for having her and assists her in the home. For Clement, his reflections pertained to the way he treated his wife prior to his diagnosis of PCa. He appeared remorseful for labelling her as ‘not being a hot-blooded’ person and acknowledged that God made her that way because he knew beforehand that he would develop prostate disease. Clement reflected on the challenges he experienced in the past to be a faithful husband at a certain age but was faced by temptations which he described as ‘the devil’s doing of putting ladies in his way’. He described his wife as humble and understanding in the midst of his erectile dysfunction for the past two years and is now appreciative of the way God made her.
Pete believed that his own doing caused his diagnosis of PCa. He described himself as having multiple partners. He believed that he should start living right.

“They said their words...but I didn’t understand what they were saying. I know right now I’m doing a lot of wrong. Right now, I may not be hurting a lot of people, but I know I do a lot of things that not pleasant in the sight of the Lord. I don’t thief. I ain’t killing, I ain’t telling people no lies and getting people in trouble and all these kinds of things but as a matter of fact at my age I still like my women and I know that that is not right in the sight of God. Too much sex...this may have caused my cancer. But I started getting rid of these ladies because I want to start living right’ (Pete, Tobago).

Pete described not understanding what his HCP told him during his consultation. He referred to his sexual lifestyle as ‘not being ‘right in the sight of God’. He reflected on his life and identified that this was his only wrong doing at that time. As such, he acknowledged a need to change his lifestyle as a means of living right with God. Charmaz (1983) described this change that Pete and Clement experienced as ‘a loss of self’. This captured the broader significance of suffering beyond the physical dimension. Just like these men, ‘loss of self’ was used to explain how individuals with chronic diseases re-evaluated their past lives as a means of losing the ‘old self’ and creating a ‘new self’ with positive attributes. This occurred most often in illnesses and life-threatening situations in which individuals prepared them spiritually and emotionally in the event of death (Charmaz, 1983). With regards to Pete, he made a decision to abort his lifestyle habits of having multiple sexual partners.

6.4.2 Shared blame

Most of the men in the study experienced shared blame that they attributed to both themselves and HCPs. This was common among men who were aware of the DRE but did not attend annually for the test. They blamed themselves for this but also believed that it was the duty of the Government and the doctors to publicize the importance of the DRE, as most men were not aware of the high PCa incidence and mortality rates in Trinidad and Tobago, as seen with Adam.

Adam shared his experiences of ‘shared blame’ in the data excerpt below. He acknowledged his ignorance of early detection for PCa and emphasized that his health care providers were silent regarding his diagnostic test results, treatment and meanings related to these. Adam believed that
this ‘silence’ contributed to significant delays in his care, which resulted in his advancing metastatic prostatic condition.

‘Well first thing because of my ignorance, and I didn’t check my prostate before. I was coming here for the longest while and nobody was telling me anything...because they did the body works and they did some x-rays. So, within that 2-month period I keep going to the hospital back and forth...back and forth...can’t walk...being frustrated. It’s as though I was in this by myself. Let’s say I was 100% dependent on the hospital to go ahead with my illness. It means they were the ones to tell me what I have been diagnosed with and to treat me they would not be able to...because I would be done dead already...I never really asked too much questions...I feel you might say it’s my responsibility it’s my prostate – I know it’s me...but you as the doctor at least take a time out to educate the patients on what is the problem...because you know it may have men like myself that can’t read and all these things....you may try to tell you something...but if they don’t speak in lay man’s terms you wouldn’t understand’ (Adam, Tobago).

Adam highlighted that his health care providers did not communicate with him along his care pathways which contributed to his frustrations (‘back and forth...can’t walk and being frustrated’), uncertainty (‘nobody was telling me anything’) and feelings of isolation (‘I was in this by myself’). Malle (2012) posited that experiences of human behaviour guide individuals’ perceptions and social cognitions of blame. These accounts described in the data excerpt above contributed to Adam’s social cognitions. In this excerpt, Adam demonstrated shared blame in which he accepted accountability for his ignorance when he emphasized that ‘it’s his responsibility’ and ‘his prostate’, and Adam also contributed to the silence that existed during consultations, which he described as ‘I never asked too much questions’. However, Adam acknowledged dependency on his providers to educate him about his prostate, his diagnostic tests results and meanings of these in order for him to have an understanding of events and processes and be taken along every step of his care pathways. Adam’s social cognitions shaped his cognitive blame of his health providers. He believed that his health care providers were morally responsible for the delay in his diagnosis and the outcome of his condition. He described this as ‘I was 100% dependent on the hospital to go ahead with my illness’ and ‘you as the doctor take time out to educate me’. Here, Adam was directly addressing his doctor through me using active voice.
Casting blame refers to men’s attribution of blame solely on HCPs. This was mainly experienced by asymptomatic men that had enrolled in clinical trials, like Mark. Casting blame was also experienced by Luke when he developed a life-threatening infection post-biopsy and some partners, as demonstrated with Lin, who blamed her spouse for his diagnosis of PCa due to lifestyle habits.

Mark experienced casting blame in which he felt that HCPs were responsible for his diagnosis of metastatic PCa.

‘They say I must do a biopsy, so I was wondering what biopsy they talking about because I had surgery and they removed the entire prostate. I was surprised to find out that they didn’t remove the entire prostate, they only took out piece. When I ask them, they said that there were vital organs nearby and because the prostate was so enlarged, they could not remove the entire prostate. Nobody told me this. I only found out the prostate wasn’t removed six months later. They have some questions to answer. I just feel aggrieved. I made sure to join this programme. I feel short-changed. They are not answering this truthfully. Because it is a layman you’re dealing with, they think they could just pass off any type of garbage to me. This is how I see it. If it had been somebody else, it may be different. I understand that some other men in that study were just like me. After so many years they left the research study and found out they had cancer. This is outrageous!’ (Mark, Tobago)

Mark expressed anger, disappointment and distrust in the health system based on the silence he experienced in the prostate research programme and the hospital. His first account of silence reflected in the data was in relation to his prostate not being removed. Unlike most of the men in the study, Mark was asymptomatic before joining the clinical trial. The agent self as ‘taking control’ was demonstrated through Mark’s motivation to enrol in the prostate research programme and entrust his care to HCPs. Heatherton & Tice (1994) purported that distrust is generated when failed efforts or failure of strength occurs among individuals that utilize self-perceived regulatory mechanisms to prevent an undesired outcome, which was experienced by Mark and other men in the study. He felt ‘aggrieved’ that his control measures did not produce the desired outcome of detecting his cancer at an early stage, which contributed to disempowerment and feelings of helplessness and blame. Mark’s experiences triggered perceptions of a prejudiced and incompetent health system. This was shown in
the data as ‘if I was properly handled’ and ‘if it had been somebody else’ and not a ‘layman’, ‘I feel short changed’ and not answering truthfully’. These contributed to feelings of neglect and exploitation, stated as, ‘they used me as a guinea pig’. Kennedy et al., (2007) highlighted that black men fail to participate in medical research because of their distrust in the medical system based on prior experiences described as ‘being used as guinea pigs’ like Mark. The medical literature highlights that any signs of advanced metastatic PCa observed when surgery commences may warrant discontinuation of prostatectomy procedure, which should be discussed with the patient prior to this (American Cancer Society, 2015; Cancer Research UK, 2015b). This may have been the case for Mark but unfortunately was never discussed with him.

Some partners, like Lin felt that her husband’s lifestyle contributed to his PCa development. She believed that this was God’s way of teaching him. Lin stated that since then their relationship had improved and that they were closer.

‘I believe that God did that to teach Tim what he was doing was all wrong. Yes, he had a lot of ladies. I would say he contributed to it, must have caused it...because what else. He eats well, he doesn’t drink or smoke. I would say that’s my belief. We have grown closer though. I remember when he found out he had cancer he came to me and he say he sorry for all the women and you know. I turn and I tell him God wanted you to stop doing that! (Lin, Tobago).

A few women also voiced their belief in the connection between sex and PCa. However, this was mainly from Tobago. The female participants from Trinidad identified alcohol consumption, stress, tobacco smoking and family history as causes of PCa development. Radley and Green (1987) describe positive illness experiences as secondary gain for individuals that view illness as providing an avenue of fulfilment. The women in the study reported how the diagnosis of cancer helped men connect spiritually with God.

Luke stated that his doctors did not inform him about taking antibiotics prophylactically due to a risk of infection in relation to the biopsy procedure. Due to this, according to Luke he developed a life-threatening infection in which he had to be hospitalized.

‘But they run tests and they say that I got an infection. But the doctor want to tell me it’s not from the biopsy, but I know it must be from the biopsy. I tell him that I came up here strong,
healthy and everything and from the time you all started doing those tests, insert that thing inside of me and start clipping away...that was what caused it. I blame the doctors for not telling me about the antibiotics – they just called me and tell me to come in on Monday. Because of this I was hospitalized for the first time in my life with a serious infection...they spoiled my record. I was never sick...and I never had to go to any hospital for anything. I never got red eye or gonorrhoea or anything like that when other men getting it...they always say I blessed, I can’t trust anybody again because of what happened. This really upset me’ (Luke, Tobago).

Luke became distrustful of doctors and blamed them for not informing him about taking antibiotics prior to having the biopsy procedure done. He explained that he had undergone several tests because of his sick feelings experienced after having the prostate biopsy. Similar to Luke, men in a UK study reported developing a post infection from the biopsy procedure (Wade et al., 2015). Some stated that the post infection hospitalization experience was worse than the biopsy procedure itself. Even though these men received prophylaxis antibiotics, they were distrustful of doctors and the medical system because of this (Wade et al., 2015). Blame is moral judgement that is both cognitive and social (Malle et al., 2012). Scanlon (2008) purported that ‘casting blame’ or blaming others can occur when norms are violated by other individuals as experienced by Luke. His norms were identified as, ‘I was never sick’; ‘I never had to go to the hospital’, ‘strong and healthy’. However, his experiences of developing a life-threatening infection changed his norms to sick and being hospitalized, which he described as ‘I was hospitalized for the first time in my life’. This change in norms was highlighted in the data excerpt as ‘they spoiled my record’. Luke believed that his doctor violated his norms, which caused him to ‘spoil’ his record of ‘never being ill or hospitalized’. Coates & Tognazzini (2012) highlighted that emotions guide the information processing of blame, as Luke experienced through being hospitalized for the first time. He pointed out that his health care providers did not accept accountability for their failure to educate him about his risk of developing an infection and the administration of antibiotics. Instead ‘casting blame’ was described in the excerpt above by Luke as, ‘but the doctor want to tell me it’s not from the biopsy, but I know it must be from the biopsy’. Dumitrescu & Ryan (2014) posited that a culture of blame existed in healthcare, in which patients were usually the victims, which contributed significantly to fear and anxiety when health care providers failed to communicate effectively and disclose medical errors (Abd Elwahab & Doherty, 2014) as seen with Luke. His personal accounts contributed to distrust in the medical system.
6.4.4 Summary of Blame and Distrust

Blame and distrust highlighted men’s and their partners’ feelings of resentment towards holding themselves, their HCPs and the Government accountable for their diagnosis of PCa. It also emphasizes the reported errors made by doctors, such as non-administration of antibiotic pre-biopsy procedure due to shortage of staff. The following category ‘Silence breakers’ describes how men and their partners were able to obtain an early diagnosis and work to break the silence that surrounds PCa.

6.5 Silence breakers

This category describes how men and their partners broke the silence along routes to diagnosis which facilitated a timely diagnosis. For example, this was relevant to Xavier due to knowledgeable social contacts within his network of friends. Men that were of a higher socioeconomic status like Cameroon were more likely to have knowledgeable social contacts and enabled them to feel able to engage in questioning and requesting information from HCPs, like Tim. Some men like Kinsley motivated other men to attend for prostate annual examinations, which created awareness of PCa screening and symptoms of advancing prostate disease. And partners such as Cherry, Paula, Jane and Tia were instrumental towards obtaining information, taking biopsy samples privately to obtain a faster diagnosis and locating specialist doctors, which enabled them to find treatment for their spouses.

6.5.1 Knowledgeable social contacts

Xavier stated that even though his doctors did not explain everything to him about his bodily changes and pre-treatment, his family members being in the medical profession were instrumental towards ‘filling the information gap’ thus breaking the silence along routes to diagnosis. This facilitated a smooth transition along care pathways for him. As such, his cancer was diagnosed and treated earlier than most men in the study.

‘I was scared, and I wasn’t sure because they didn’t really tell me what it would be like for the tests and my treatment. I had never been in the hospital before, but I was properly well taken
care of because my niece is a doctor. My wife’s niece is a doctor too and there is a nurse who I know. And all of them would come and check me from time to time at San Fernando hospital at the urology ward and they will sort of tell me what was happening each time, so I was no longer afraid. They have a urology clinic too, but I got proper treatment. I had to take the biopsy three times. Well I believe that they wanted to see everything and as fast as they go through the procedure they said well look go and take a blood test. Take an x-ray for here (pointing to abdomen). The second to last biopsy I had to go to Mount Hope. You know the biopsy cost $10,000 if you’re doing it privately. But I got a paper and I had it done free at that hospital. Well it was a doctor I know who arranged the biopsy for me. It was my wife’s niece who sorted that out for me. They also sent me for a bone x-ray. They gave me a paper to go to Mount Hope. And it wasn’t a problem because one of my wife’s brothers well he’s working at Mount Hope. He also sorted that out for me. I bounce up nice doctors there also’ (Xavier, Trinidad).

Xavier shared his experiences at the public health system. Initially Xavier described feeling fearful of going to the hospital for tests because of his uncertainty stated as, ‘I wasn’t sure’. However, Xavier’s social network formed by his family members, relatives and other contacts in the medical profession guided him throughout his care pathways as seen in the excerpt. This contributed to a positive experience for him because he was no longer uncertain or fearful as information was provided to him about his PSA test, biopsy procedure and treatment. Additionally, he was guided each step of the way along his care pathways, as evidenced when Xavier stated, ‘as fast as they go through the procedure they said well look go and take a blood test’. Very few men in the study were privileged to have a knowledgeable social network like Xavier. And most of the men reported that they paid for diagnostic tests and procedures at both public and private health systems.

6.5.2 Men of higher socio-economic status

Men of a higher socioeconomic status were seen as silent breakers by requesting PSA tests and DRE examinations on an annual basis. These were facilitated through private medical insurance on an annual basis. Cameroon indicated that he requested PCa screening annually from his private doctor.
‘Well, I am at risk. I don’t have anybody in the family with PCa but being Black still puts me at risk. I usually ask my doctor every year to do these tests. The last time I did it... it was about 2 or around there. I started this when I was around 45. I go privately. I have medical insurance so that covers all these tests. Every time the doctor does the PSA, I always ask them how its reading so I would have an idea if its high or low; or how the prostate feeling. I can’t be bothered about how men see this as a homosexual thing. Yes, it can be painful. But I go in to do it and within a few minutes it’s over. I like to take precautions just to make sure I am cancer free and if anything is there at least the doctors can pick it up early. I generally keep fit, I eat well. That is usually my lifestyle’ (Cameroon, Tobago).

Cameroon stated that had been actively involved in PSA and DRE testing on an annual basis. He is knowledgeable about early detection of PCa and acknowledges his risk of developing PCa based on his ethnicity. Cameroon emphasizes the associations of the DRE with homosexuality and pain for TT men. This was a common finding among men in the study. Cameroon stated that he requests PSA and DRE tests from his doctor every year and enquires about the results of his tests. He indicated that he is taking precautions towards his prostate health. This was found across the group for men of higher socioeconomic status.

6.5.3 Men that engaged in questioning and requesting information

Unlike Cameroon who requested PSA and DRE tests through their private doctors, a few men also engaged in questioning and requesting information from HCPs in the public health systems amidst the busy clinics. Tim stated that he usually questioned doctors in order to have a better understanding of his prostate health.

‘I was diagnosed with Stage II PCa although I did annual check-ups. I noticed that the doctors don’t really like to talk to patients about their problems and treatment as such unless you question them. And that is the thing, they don’t like to be questioned as well. I question them because I need to know what is happening. Like a doctor told me about the different types of treatment but he didn’t specify what sort of complications might occur afterwards. He only
gave me the good but not the bad. I want to know both sides of it. I think that may be part of my job as a police officer. After questioning all types of people for so many years, you develop confidence in dealing with anybody’ (Tim, Tobago).

Tim believed that his questioning and requesting information may have been related to his job as a police officer. He stated that his experiences of working in this capacity may have contributed to his ease of confidence in asking questions and requesting information from his doctors. Tim shared that his doctor did not provide him with sufficient information regarding his treatment. This triggered his questioning. He also pointed out that doctors did not like his questioning.

6.5.4 Increasing public awareness about PCa

Most men like Kingsley that were aware of their diagnosis of PCa were involved towards increasing awareness of the disease within their workplaces, churches and families.

‘I got involved in prostate clinics as the doctors asked me to sort of promote awareness of PCa to help men come forward. What the doctors are saying is that Black men don’t come forward and when they do it’s too late. This is what is causing us to die early. I didn’t know about it. Thank God for a girlfriend who was working as a cleaner in the clinic. She told me that a lot of men dying from this thing and she said you better get checked. She said that some men have it and it wouldn’t show any signs. And that was what got me here in the first place. I didn’t know that they could test for these things. I thought that all men will eventually die from PCa and nothing can be done. So now that I know I tell men in my family. Well I am a party man I love to dance. I enter competitions as well. So, people know me very well in the village so maybe that’s how the doctors ask me to get involved and ask men to come in. I even talk to young fellas so they would be warned early. I want to live to see all my children and grandchildren grow up’ (Kingsley, Tobago).
Kingsley highlighted that he only became aware of PCa screening and the asymptomatic nature of early stage prostate disease through a social contact. This motivated him to become involved towards increasing public awareness of PCa. Kingsley’s knowledge caused him to act as a silent breaker within his community. He also identified doctor’s communication about men’s late help-seeking behaviours and the PCa mortality rates associated with this.

6.5.5 Partners involved in men’s prostate care

Partners were also instrumental towards men’s prostate care. They acted as ‘silent breakers’ within consultations with doctors, which helped smoothen the journey for men. For example, at a public health system Paula requested her husband’s biopsy samples. She stated that she had taken these samples to a private health system to obtain a faster diagnosis. Jane highlighted that she requested assistance from a doctor abroad to commence treatment for her spouse to decrease the long waiting time in the public health system. Cheryl perceived that her questioning was seen as ‘loud’ and Ria highlighted that talking about her spouse’s experiences during the focus group interviews helped her to unburden matters concerning her husband’s health that she had kept to herself.

Paula is a 50-year-old housewife who had been attending appointments with her husband. She described severe delays in scheduling appointments for diagnostic procedures and obtaining reports for these. The data extract below highlighted Paula’s roles as an information seeker and support agent. She was also instrumental towards decision-making for her spouse.

“But my problem is when you have to get a test done, it takes too long. Like with him, he has to get a bone scan and a CT scan and when we made the appointment here, they telling (told) us is next six months. Within that six months anything could go wrong with him. So, I told him let’s go private rather than wait for all that time. Because if I have to wait six months for my husband to get an appointment, it come like I’m putting my husband in death doors. Right now, when I’m finished here. I have to go downstairs to find out more about this because they told me that they have a lot of people on the list for the bone scan especially, so I have to also check on the CT scan because they have his paper. If I get a good appointment, no problem I will take it. If not, I am taking it out and I will go back outside and let him get his bone scan and CT scan. We had to take the biopsy vials to a private place in St Joseph in order to speed it up. I have the thing here for the lab. (Paula, Trinidad)
Paula expressed anxiety over waiting for six months to get an appointment for her husband. She was determined to go privately in order to decrease diagnostic delays so that her husband could receive treatment in a prompt manner. This was evidenced when Paula made a decision to take specimens to a private laboratory. Paula’s executive self was highlighted in the data excerpt as taking control and making decisions towards her husband’s care.

Jane’s experiences were related to silence with regards to her husband’s treatment. Jane, a 59-year-old private business owner explained that she got married to Jake after he had his second biopsy. She researched the internet for information regarding the prostate and prostate disease in order to get a better understanding of her husband’s health problems.

‘When he had the second biopsy, it took about 2 months or more before the doctor called him, which I couldn’t understand. I heard that the doctor had left Trinidad and he didn’t say anything. This was after the doctor told him that it was cancerous. He didn’t explain what will be the next steps and just left him hanging like that. I was flustered and I wasn’t happy about it. So, this is how I decided to do some research. I decided to take matters in my own hands. He was getting a lot of back pain. I went on the internet and I contacted somebody from Israel who was based in Miami Florida. About 2 weeks after we made contact, he came to Trinidad. Well I had told him what my husband was going through and explained everything to him over the Internet. He does the surgery for it, but he doesn’t cut he inserts something. I think it’s robotic. He explained everything and gave information about everything, which we were not getting. He told us that even though we were going to have the surgery in Miami, it was better to do the tests here because it would be better. Miami would be more expensive for us if we had it done there.’ (Jane, Trinidad).

In the data extract above, Jane described the two-fold silence experienced. Jake was unaware of his treatment plan and did not ask questions about this. This occurred after Jake learned of his PCa diagnosis. Jane felt that her husband was abandoned, and this motivated her ‘to take matters in her own hands’. Jane became involved in her husbands’ care after he described feeling ‘fed-up’. She researched health sites on the internet and made contact with a cancer specialist in Miami who discussed robotic surgery, which was one treatment option. Jane’s role as information seeker, and
health manager were highlighted in this extract. This concurs with Boehmer & Clark (2001a) findings which showed the numerous roles that women play as key agents in their spouses’ care. Both Jane and Jake appeared satisfied about the information they received from this cancer specialist.

Cheryl is a housewife and retired schoolteacher who had been attending clinic with her husband, Adrian. She highlighted the issue of silence that existed among nurses which she responded to by asking questions pertaining to her husband’s care. She perceived that nurses might have attributed her questioning as ‘loud’ and ‘being a bother’.

‘The nurses here don’t like you to bother them. I spoke to a few of them and I didn’t like how they attended to me. I think it’s the attitude which comes when they’re busy. Nobody likes talking...everybody’s quiet just doing their job and when you ask a question, they don’t like it. I asked them if another doctor could see my husband and what’s happening. They probably think I’m loud but how will we know what’s going on’ (Cheryl, Trinidad).

Cheryl requested for another doctor to attend to her husband because of the uncertainty and delays in making appointments. She identified how her questioning upset the ceremonial order of the clinic (Strong, 1977) as displayed by the attitudes of the nurses. Cheryl’s approach as a ‘silent breaker’ was demonstrated through confrontation in which she made a request as seen in the data excerpt. Cheryl stated that expressing her concerns through voice triggered nurses’ attitudes displayed in their body language. Attitudes have been purported to be part of our beliefs, which can be negative or positive and defines who we are and manifests behaviourally, through our body language, choices and relationships (Communication Institute for Online Scholarship (CIOS), 2015). HCPs attitudes have been viewed as core to the provision of health care, in promoting a positive well-being when a caring attitude is portrayed to patients. Negative behaviours can negatively affect the relationship with patients (Price, 2015). Cheryl perceived that nurses’ attitudes were formed because of the demands of the profession. Her perceptions were also shared by men in this study and in the literature, in which people from the public health sector held perceptions that an HCP role is busy which should be understood primarily because of the workload and the increasing hospital admissions, shortage of staff and working conditions experienced (Brekke et al., 2007).
Ria’s experiences of breaking the silence were not in relation to asking HCPs questions or requesting information as experienced by the other partners. She identified that talking about her husband’s health problems during the focus group was very helpful for her towards releasing her burdens.

_I don’t really like talking about my husband’s problems. This is the first time I’m here sharing with other women. I like this...sharing with other women. I feel as though my burdens are released somewhat. It’s good to talk about these things. Now I see the importance of talking about these things. My husband never wanted anyone to know so we kept it to ourselves. But it helps to talk about it...at least for me. I wish this group can continue’ (Ria, Tobago).

Ria’s account of breaking the silence highlighted the importance of support groups for partners of men with PCa. Additionally, the presence of a social network has been seen as a major support system for people of African descent (Triandis, 2002). Ria’s accounts’ of feeling burdened reflects Radley’s (1994) contribution to how the illness burden is shared when one partner is diagnosed with an illness. Reports of non-disclosure have been identified among couples as a coping strategy towards PCa diagnosis (Harden et al., 2002; Gray et al., 2000b). Currently, there is no support group in place for both PCa patients and partners within TT. This was highlighted in one meeting with the head nurse of the Tobago Oncology unit. This has implications towards coping and support along the trajectory of care.

6.5.6 Summary of the category of ‘Breaking the silence’

Breaking the silence illuminated women’s roles along PCa care pathways and how they coped with the silent wall developed in consultation between HCPs and their spouses. The two-way silence experienced; that is their husbands’ accounts of HCPs silence and their reciprocal silence served as a trigger for them to become empowered through researching the internet and increasing their awareness of PCa, diagnosis tests and treatment. This enabled them to ask questions and request information on behalf of their spouses. Women did not go along with the silence of assent that was evident in the narrative of the men when talking about their experience of health services. Women reported enabling their partners to progress in their pathways to diagnosis and treatment by various forms of support and intervention.
6.6 Chapter Summary

This chapter discussed men and their partners’ diagnosis and post diagnosis experiences as it pertained to the categories, ‘Disconnected to health services, The Wall of Silence’, ‘Blame and distrust’ and ‘Breaking the silence’. Participants accounts of self-silences as well as silence from their providers contributed to men’s feelings of disconnectedness, uncertainty, blame and distrust in the medical system. Men’s experiences of self-silences were related to lack of self-confidence, masculinity and a lack of invitation from HCPs to ask questions or request information. White coat silence was experienced by men who kept quiet whilst interacting with HCPs due to their expectations that patients should be quiet, passive and avoid talking during clinic sessions. HCPs silences along routes to diagnosis provoked dimensions of blame among men when they were diagnosed with PCa. These types of blame were related to themselves with regard to their self-contributions to development of PCa; and to HCPs for not picking up their cancer at an earlier stage and providing treatment for this in a timely manner. Silent breakers described participants that contributed to questioning and requesting information. This was demonstrated through men’s family members that were HCPs who acted as their voice in the midst of provider silence. These men were diagnosed with early stage prostate disease. Men from higher socioeconomic backgrounds and those that requested PSA and DRE screening annually were also diagnosed with early stage PCa. Women acted as silent breakers by trying to smooth the journey for men through requesting information on their behalf, seeking medical decisions privately and internationally and questioning HCPs concerning their spouses’ well-being. Men that were diagnosed with PCa became involved in health promotion towards breaking the silence among men in their communities about the asymptomatic nature of early stage PCa, PSA and DRE screening and the myths and connotations attached to these. In the next chapter I discuss findings in relation to the substantive theory that was generated from these and its connection with the wider literature.
CHAPTER SEVEN – DISCUSSION AND SUBSTANTIVE THEORY

7.1 Introduction

This is the first explorative study conducted in this twin isle to capture men and their partners’ experiences along routes to diagnosis of PCa, which achieved the overarching aim of the study. To better understand how they experience PCa in TT, this study captured social processes inclusive of macro and micro factors through using Straussian Grounded Theory Methodology and identifying men and their partners’ beliefs, perceptions, knowledge, interactions with HCPs and health systems and their meanings of the experience. Many factors impacted men’s journey through diagnosis and treatment for PCa including barriers and facilitators to care during appraisal, help-seeking, diagnosis and treatment of PCa in the context that men in the Caribbean are known to die early of PCa and late diagnosis was a major contributor to early death and emergency admission to hospital with advanced and metastatic symptomatic presentation.

The purpose of this chapter is threefold. I first discuss the substantive theory of silence that has emerged through this study (Figure 12). I provide a definition of what silence means from the data and highlight the categories that comprise this silence. I outline underpinning attributes and related concepts and expound on how connections occur within the substantive theory that give rise to contributors, consequences, resolution and adaptation. I shed light on how this theory contributes and impinges on men’s experiences of PCa experiences and pathways and demonstrate how my findings provide new insight and understanding of the concept of silence as it relates to men’s prostate health in TT, and the wider literature. These findings are compared and contrasted with current research literature to highlight its applicability to PCa health research.
I revisit the research questions that were raised in the introduction chapter and show how I have extended existing knowledge on barriers and facilitators to care, which contributes to a more comprehensive understanding of problems related to progression along PCa care pathways for men in TT. The central research questions were: What are the experiences of men and their partners along care pathways for PCa in TT? What are newly diagnosed men and their partners’ beliefs of their illness during their journey to diagnosis and treatment of PCa in TT? Why do men access healthcare services late in TT? What are the differences between the experiences of men and their partners in the two islands of TT? The emerging theory of silence presents potential explanations for men and their partners’ experiences of care pathways for PCa in TT.

Lastly, I acknowledge the limitations of the study and discuss implications for clinical practice and future research. I emphasize the relevance of beliefs, culture and masculinity for inclusion to the revised Andersen model of pathway to treatment. Recommendations for further research from a multiple approach are presented along with a dissemination plan.

7.2 The theory of silence among Afro Caribbean men with PCa (SAACM)

The theory of silence among Afro Caribbean men was generated from the data and is based on the finding of different types of silences before and along care pathways during men’s experience of symptoms and eventual entry to care pathways. Silence significantly impacts men’s appraisal of symptoms, help-seeking behaviours, timely diagnosis of the disease and men’s compliance to treatment and follow up care. This substantive theory will be referred to by the acronym SAACM and provides a holistic approach to identify men’s accounts of progression along care pathways for PCa. SAACM encompasses the components of patient, provider, systems and environment, and is organized around six major themes: (i) antecedents of silence, (ii) power and silence, (iii) contributors, (iv) consequences, (v) adaptation, and (vi) resolution of silence. These will be discussed later on and is represented in diagrammatic format in Figure 12, which outlines these components.
Table 18 on the following page is representative of research participants’ accounts of the types of silences that occurred along routes to diagnosis for PCa in TT. This is mapped in relation to the wider literature and connects with recommendations arising from the study that are discussed later on.
### Table 18: Types of silences along routes to diagnosis for PCa in TT and in relation to the literature and links with Recommendations (*)

<table>
<thead>
<tr>
<th>DISRUPTING THE SELF (see 7.2.1)</th>
<th>DISCONNECTED TO HEALTH SERVICES (see 7.2.2 and 7.2.3)</th>
<th>THE WALL OF SILENCE (see 7.2.2 and 7.2.3)</th>
<th>BLAME &amp; DISTRUST (see 7.2.2 and 7.2.3)</th>
<th>BREAKING THE SILENCE (see 7.2.1)</th>
</tr>
</thead>
<tbody>
<tr>
<td>- non-reporting and omission of symptoms to HCPs (pg. 185 Adam, pg. 186 Ron) fear of a negative outcome, protection of masculine image, shame and embarrassment, lack of trusting doctor-patient relationship)</td>
<td>- HCPs reticence (Nobody told me) re: PSA, DRE, radiographic reports (pg. 203 Clement, pg. 204 Luke)</td>
<td>- Two-way silence (both HCPs and men in consultation) silent together (pg. 209 Greg)</td>
<td>- dissatisfied silence (silence due to long waiting times, delayed appointments and late diagnosis; voiceless; constrained communication) (pg. 214 Adam)</td>
<td>- Partners as silence breakers (sourcing and researching information, questioning and requesting information from HCPs, movements between private health systems to hasten diagnosis and treatment) (pg. 222-225 Paula, Jane, Cheryl, Ria)</td>
</tr>
<tr>
<td>- non-reporting of use of herbs and TH (pg. 191 Baxter; pg. 189 Alex) (resilience, stoicism, links with slavery and Black men bearing painful symptoms)</td>
<td>- Men's reciprocal silence (I didn't ask) (pg. 201 Mark)</td>
<td>- relational silence (pg. 208 Leo white-coat silence) (men keeping quiet to protect doctor-patient relationships)</td>
<td>- resistant silence (silence due to feelings of being exploited and used in clinical trials) (pg. 215 Mark)</td>
<td>- men informing other men to get tested for PCa through annual PSA and DRE, demystifying early PCa asymptomatic nature (pg. 222 Kingsley)</td>
</tr>
<tr>
<td>- imposing silence (due to lack of touch and eye contact, rushed appointments and perceptions of uncaring profession) (pg. 204 Luke)</td>
<td>- silence in men due to suppression of voice (power imbalance in doctor-patient relationships – perceptions wives could not understand their journey) (pg. 201 Mark, Clement pg. 194)</td>
<td>- bureaucratic silence (HCPs focus on doing administrative duties to speed up clinic in the midst of high patient workload and shortage of staff and avoidance of verbal communication) (pg. 206 Adam)</td>
<td>- quiescence (silence due to fear of the consequences of speaking up) (pg. 215 Mark, pg. 217 Luke)</td>
<td>- men from higher socioeconomic status (pg. 220 Cameroon) (questioning HCPs and requesting information) (pg. 221 Tim)</td>
</tr>
<tr>
<td>- silence around cancer (death and stigma) (pg. 208 Leo white-coat silence)</td>
<td>- imposed silence (due to lack of touch and eye contact, rushed appointments and perceptions of uncaring profession) (pg. 204 Luke)</td>
<td>- pro-social silence (HCP withholding of PCa diagnosis) ** (most of the patients)</td>
<td>- awkward silence (extended periods of silence, lack of invitation to ask questions, uncertainty) (pg. 207 Paul)</td>
<td>- men with knowledgeable social contacts (pg. 219 Xavier) (relatives that are HCPs)</td>
</tr>
<tr>
<td>- prayerful silence to God for direction (Pete, 213)</td>
<td>- silence due to self-protection or avoidance of danger)</td>
<td>- disengaged/ineffectual silence or acquiescence (men’s perceptions of not being able to effect change resulting in disconnect and relationships) (pg. 209 Greg; pg. 207 Paul)</td>
<td>- ceremonial silence (role of good patient: do not ask questions, remain passive; passivity) (pg. 209 Greg)</td>
<td>- praying to God to cope with PCa (pg. 210 Matt)</td>
</tr>
<tr>
<td></td>
<td>- silence due to privacy: self-protection or avoidance of danger)</td>
<td>- different silence (pg. 206 Adam) (men were silent due to lack of self-confidence; men with low literacy, low socio-economic status)</td>
<td>- needed silence (empathetic/compassionate/coping silence, (pg. 195 Petra) when disclosing the diagnosis of cancer)</td>
<td>- partners talking about husbands’ journey as a way of coping (pg. 225 Ria)</td>
</tr>
<tr>
<td></td>
<td>* (7.3.1.2) POLICY MAKING re: pathways to care for PCa</td>
<td>* (7.3.1.3) STAFF TRAINING &amp; EDUCATION (communication)</td>
<td>- silence due to self-blame (pg. 210-211 Matt, Jason, Clement, Pete, Lin pg. 216)</td>
<td>**PARTNERS TRAINED AS ADVOCATES (use of prostate radar tool), support groups (Focus of post-doctoral research)</td>
</tr>
<tr>
<td></td>
<td>*(7.3.1.3) STAFF TRAINING &amp; EDUCATION (communication)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The substantive theory of silence identifies how Afro-Caribbean men in TT (see Figure 12) experience routes to diagnosis for PCa. Men reported that doctors were silent regarding test results, diagnosis and treatment options with them. Men also experienced a reciprocal silence due to feelings of embarrassment, lack of trust in doctors and inequalities in how they viewed their relationships with healthcare providers. The silences identified led men to experience feelings of blame and distrust in healthcare professionals and health systems for their late diagnosis of cancer.
Figure 12. The theory of silence among Afro-Caribbean men (SACCM) in TT

**CONTRIBUTORS OF SILENCE**
- Uncertainty
- Lack of awareness
- Delays in healthcare
- Shortage of staff
- High patient-doctor ratio

**SELF**

**ANTECEDENTS OF SILENCE**
- Hegemonic masculinity norms
- Lack of knowledge
- Lay health beliefs & practices

- Stoicism
- Self-reliance
- Concealment of vulnerability

**SILENCE**
- Nobody told me
- I didn't ask
- I couldn't answer

**HEALTH SYSTEMS**

**POWER & SILENCE**
- Power imbalances in relationships
- Ceremonial silence
- Imposed silence

**HEALTH PROVIDERS**

**RESOLUTION FACTORS OF SILENCE**
- Information
- Social capital
- Role of women
- Public health awareness
- Trusting relationships

**CONSEQUENCES OF SILENCE**

**Initial stages**
- Uninformed
- Don't recognize symptoms
- Unable to voice
- Misinterpret symptoms
- Don't seek help

**Subsequent stages**
- Disempowerment
- High symptom burden
- Late diagnosis
- Poor prognosis
- Blame & Distrust

**ENVIRONMENT**

**ADAPTATION TO SILENCE**
- Spiritual connectedness
- Self-care
- Fear
- Disconnect & isolation
7.2.1 Men’s report of their silence during pre-diagnosis and symptom journey

Here, I address the research question, ‘Why do men access health services late in TT? The concept of silence in reference to the current study resounds with non-disclosure silence in relation to PCa studies, anthropology literature and organizational communication research. These are highlighted as: silence relating to omission of information with HCPs and men’s silence in relation to non-disclosure of symptoms with wives. These are discussed under the aforementioned headings.

Men’s accounts of silence concerned their non-reporting and omission of health information within relationships that is between men and HCPs and among couples. Men in the current study were reticent to communicate about bodily changes, such as severe back pain and erectile dysfunction with HCPs and spouses. With regard to silence with HCPs, a major reason coming from the findings pertains to power imbalances in provider-patient relationships, which will be discussed fully in 7.2.4.

7.2.1.1 Silence in relation to men’s omission of information with HCPs

Men’s attitudes were reported to be connected to slavery, as the health system was viewed by some as being linked to colonialism and the White man’s influence on changing their cultural beliefs and practices. As such these men viewed conventional medicine as toxic and harmful in comparison to herbal medicine, which was deemed as natural. These cultural beliefs may have impacted masculinity norms as Black men perceived that they should silently bear painful symptoms as a mark of strength.

Men’s perceptions of bearing painful symptoms silently in the current study were also related primarily to the taboo and stigma surrounding cancer and the impact of symptoms on their masculine image. With regard to the former, some men were silent towards saying the word ‘cancer’ and did not visit the doctor for painful symptoms until these became unbearable and disruptive. Men’s silences were based on their perceptions of cancer as being equated with an incurable disease, death and dying, fatalism or punishment from God and as a consequence of demons. They also wanted to avoid being seen as weak or vulnerable in the eyes of their
spouses, families, friends and HCPs hence omitting information about symptoms to HCPs. Men’s perceptions of cancer as a death sentence and as a result of demons and fatalism aligns with Sontag’s stance on how people view illness based on stereotypes that exist in societies. She highlighted that metaphors and myths about cancer can impact suffering as these empower individuals’ view of cancer as a curse or a punishment, rather than a disease that can be treated (Sontag, 1978). In relation to the latter point, that is, the impact of symptoms on men’s masculine image, being silent about erectile problems and other symptoms experienced were seen as preserving their masculine image as it was taboo to discuss these with others. This was due to the stigma attached to impotence as feeling emasculated, affecting relationships and shame and embarrassment. Although these experiences were shared among men in the current study, there were cultural differences in health behaviours demonstrated. For example, most Tobago men omitted health information to HCPs in order to maintain their role as breadwinner to provide for their families. Whereas, in addition to preserving their masculine image, some Trinidad men that were not breadwinners delayed help seeking because of religious and cultural beliefs. These findings correspond with Oliffe’s premise that society and culture impact men’s health behaviours in different ways: on micro level and macro level (Oliffe, 2009). Micro level factors in the current study refer to men’s personal beliefs and perceptions, such as their view of cancer. Whereas, some macro level factors are health system elements and societal norms, which are discussed more fully later on.

Apart from slavery and taboo and stigma, silence in regard to omission of information to HCPs was also reported by men to be based on a lack of trust and distrust in TT health systems. These pertained to symptoms such as severe back pain, impotence and blood in the urine. Lack of trust towards HCPs caused some men to seek alternative forms of healthcare, such as herbal use in favour of mainstream healthcare. Precipitating factors were identified as lack of therapeutic relationships with HCPs, lack of touch, ‘rushed appointments’, feelings of disregard and disconnectedness from the silence experienced in consultations. Men valued a trusting relationship, a caring environment and rapport with HCPs to discuss sexual and other health concerns. Men voiced a greater trust in their religious and traditional leaders than HCPs due to their shared belief systems, a caring atmosphere and openness. These criteria for fostering trust were also echoed in studies that examined why African men chose to consult with THs for health problems (Gage et al., 2009; Labhardt et al., 2010).
This type of silence in relation to omission of information by the men was made visible in relation to quiescence, acquiescence and defensive silence, as purported by Van Dyne in organizational communication literature (Van Dyne et al., 2003). These were defined as fear of consequences of speaking up (quiescence), disengagement due to perceptions of not being able to effect change (acquiescence) and for self-protection and avoidance of danger (defensive silence) (Van Dyne et al., 2003). These types of silence align well with a few studies in which men omitted important information that pertained to the same serious health concerns in their conversations with doctors (Boehmer & Clarke, 2001a, 2001b; Nanton & Dale, 2011). However, the current study advances how these types of silences are connected with PCa literature. Some of these new insights link with post-colonialism and slavery.

7.2.2 Silence in relation to non-disclosure of symptoms with wives

In the current study some women observed men’s frequent urination patterns, facial grimaces and changes in men’s gait indicative of severe pain. Some women did not discuss these observations with their spouses. Partners’ experiences of silence were in deference to their husbands’ position as head of the household and breadwinner and respect for their manhood. This was mainly found among Tobago partners. This was echoed in one anthropological study in which women from the Igbo tribe were silent as a mark of respect towards their husbands (Nwoye, 1985). However, this finding contrasts with that of Trinidad women who report they were more vocal in consultations, which may have been contributory to their role as the main breadwinner in the family. The current study highlights one major difference between experiences of men and partners in both islands. Spousal silence in relation to respect was also identified in Harden’s study in which husbands requested that their wives refrain from asking questions during consultation (Harden et al., 2002). And some wives were cautious during interviews when asked about their husbands. This was interpreted as ‘maintaining partners sense of manhood’ in (Ervik et al., 2013), and was connected to masculinity norms. Nonetheless the current study underscores the impact of cultural beliefs as instrumental to Afro-Caribbean men’s PCa experiences.

In regard to couples, men initially did not disclose information to their partners about their bodily changes, such as urinary, sexual changes and pain, and isolated or withdrew physically and emotionally in order to cope. Silence reported within relationships was ‘to protect their spouses, fear of spousal abandonment and death and dying. Men’s perceptions that ‘being sick’ would put a strain on the relationship and expose their vulnerability were also highlighted. This
was mainly due to perceptions of family roles, which were linked to cultural beliefs and seen mostly among Tobago participants. This was a way of protecting their vulnerability in response to the emotional reactions and potential outcome of these symptoms. As such men resorted to privacy and isolated themselves from their spouses for self-protection and to cope with these fears and emotional reactions. TT men’s silence corresponds with Oliffe (2009) premise on cultural discourses that men attribute towards masculinity expressions, which are in opposition to feminism, such as denial of painful symptoms. This he describes as “antitheses of stoicism and self-reliance” (p. 347) and the ‘shifting social constructions of masculinity’ in relation to age, culture, social class and illness. However, what differs in the current study is that similar hegemonic masculinity norms were demonstrated by all men regardless of age, social class, culture and stages of PCa. Whilst silences experienced by men differed along routes to diagnosis for PCa, hegemonic norms remained constant pre-diagnosis, at diagnosis and during treatment.

The attribute of ‘non-disclosure’ with regard to relationships also resonates with that of relational silence according to Brinsfield’s definition. This is related to keeping quiet to protect relationships (Brinsfield, 2003). This type of silence agrees with studies that identified men’s non-disclosure of symptoms and their emotions along care pathways for PCa (Boehmer & Clarke, 2001a; Kelly, 2009; Krumwiede & Krumwiede, 2012; Wenger, 2013). One main reason highlighted across studies was not to burden their spouses and this was identified as a barrier to effective communication in the husband-wife relationship (Boehmer & Clark, 2001a; Kelly, 2009; Krumwiede & Krumwiede, 2012; Wenger, 2013). However, what the literature lacks is an in depth understanding of Afro-Caribbean men’s cultural differences in relation to ethnicity and religion in context of PCa experiences. This study adds to Rivas et al. (2016) systematic review. It highlights how silence impacts the relational aspects of men and partners from varied cultural and ethnic backgrounds. It emphasizes how participants from both islands have unique experiences, which reflect the more visible African ethnicity and cultural beliefs in Tobago in comparison to multiple representations of ethnicities and cultural beliefs among Trinidad participants.

The attribute of non-disclosure in relation to an inability to freely communicate symptoms such as back pain and urinary changes was mirrored in a few PCa studies whereby men were reticent about their feelings and emotions with their spouses and significant others during the first year of the PCa diagnosis and at various stages of care pathways for this disease (Boehmer & Clarke, 2001a; Gray, 2000a; Nanton & Dale, 2011; Wall et al., 2013). Those that opened up to colleagues
explained how difficult it was to do so (Wall et al., 2013). This concept of non-disclosure between couples was echoed in Boehmer and Clarke’s study. However, reasons underlying men’s decisions were not explored (Boehmer & Clarke, 2001a). Gray’s study linked non-disclosure between couples as a coping mechanism to minimize the disruption of the illness (Gray, 2000a). Similarly, men did not communicate with their wives about bodily changes such as those mentioned including back pain and urinary changes (Boehmer & Clarke, 2001a, b). Fear, shame, feelings of insecurity, and protection of manhood were contributing factors to men’s non-disclosure with providers and their wives in other studies (Boehmer & Clarke, 2001a; Nanton & Dale, 2011). Shame, feelings of insecurity and protection of manhood are congruent with Kelly’s (2004) stance on how embodied changes, such as impotence threatens male identity and sexuality in relation to prostate disease. For these reasons, men in the current study omitted information to their wives. The current study draws attention to relationships between aspects of silence and masculinity, which are not highlighted in organizational communication literature. It also stresses an examination of cultural beliefs in context of masculinity that are deficient in the literature.

7.2.3 Men’s report of silence along routes to diagnosis for PCa in TT

Here, I address the other research question, ‘What are the experiences of men and their partners’ along routes to diagnosis for PCa in TT? Men’s accounts of silence occurred during interactions with HCPs. This will be discussed under the headings men’s accounts of doctors’ reticence and men’s report of self-silences.

7.2.3.1 Men’s account of doctors’ reticence

Another aspect of non-disclosure in the current study that occurred during the initial contact with HCPs during pre-diagnosis and diagnosis was in relation to men’s account of doctors’ silence in consultation. Men recalled not being told of their PSA test results, meanings of the PSA test and other diagnostic tests and results, information about treatment, side effects and follow up care. As such men experienced feeling unprepared for diagnostic tests and the treatment regime. This contributed to fear, anxiety and pending uncertainty. Doctors’ reticence was
interpreted by participants as being more prescriptive rather than empathic. This pertained to men’s accounts of doctors’ placing more emphasis on writing prescriptions and scheduling appointments, rather than towards verbal communication and a caring attitude in consultations.

Non-disclosure in relation to doctors’ reticence resonates with Walsh’s study in which GPs collected blood samples for PSA tests without informing men of this (Walsh & Hegarty, 2010), as well as in Ervik’s study whereby reports of non-disclosure of information that pertained to the significance of the PSA test and its reliability were highlighted (Ervik & Asplund, 2012). This type of silence also supports Sinfield’s study in which men were not told that they were being tested for cancer neither were they offered any information about their cancer diagnosis (Sinfield et al., 2008). Doctors’ reticence reported in the current study reflects pro-social silence as purported by Van Dyne et al. (2003), which is highlighted as ‘the withholding of work-related ideas, information, or opinions with the goal of benefiting other people or the organization, based on altruism or cooperative motives’ (Van Dyne et al., 2003, p. 1368). The withholding of information such as a cancer diagnosis has been highlighted in cultural studies as a norm for protection from psychological distress (Grassi et al., 2005; Pang et al., 2013; Taghipour et al., 2010, Tsoussis et al., 2013). The attribute of non-disclosure with regard to written communication and avoidance of verbal communication reflects bureaucratic silence, as highlighted by Chapman (1994). This refers to the emphasis reported by the men on the running of an organization from the context of procedures and duties with non-disclosure of information that is critical towards this (Chapman, 1994). This concurs with studies in which men felt doctors were too clinical or distant in their communication focussing more on the disease than the patient as person (Milne et al., 2008; Nanton & Dale, 2011, Harden et al, 2002). This study provides unique explorative insight into men and partners’ PCa experiences by highlighting the implications of silences on men and partners’ well-being in context of increasing patient workload and shortage of staff. This calls attention to support for doctors during these time constraints and heavy workload. This is further discussed under recommendations.

7.2.3.2 Men’s report of self-silences during diagnosis and post diagnosis journey

In the current study non-disclosure in relation to relationships was demonstrated between men and providers. Men identified certain factors that prevented relationship building between them and doctors. Multiple physicians, short or rushed consultations, a standing doctor or those that
did not utilize touch nor conducted physical examinations were reported. Silence in provider-patient relationships also reflect the concept of power imbalances and are discussed in 7.2.4.

In the current study non-disclosure due to lack of self-confidence was highlighted mainly among men from lower socioeconomic backgrounds. Men voiced that their low literacy was responsible for their inability to question doctors and voice concerns. A few university educated men also held this belief that doctors should not be questioned. This was echoed in Fry’s study as a sign of respect for Afro-Caribbean and Somali men (Fry, 2017). However, in the current study this was related to their perceptions of the patient’s role as being passive, and acknowledgement of doctors as experts, which were highlighted in the current study as one aspect of the category, ‘I didn’t ask’. This type of silence was mainly related to men’s lack of knowledge. However, those that were knowledgeable reported being empowered sufficiently to question doctors. One interesting finding in the current study was that mainly men that were retired police officers were able to question doctors. This may have been related to their former positions of authority, specifically towards investigative questioning (Powell et al., 2009). This highlights that a lack of self-confidence may not only occur due to illiteracy but also in part to perceptions of men’s ‘position as patient’ and is associated with ‘power and silence’ as highlighted in 7.2.4.

Non-disclosure due to a lack of self-confidence in the current study corresponds with diffident silence as highlighted in Brinsfield’s study. This relates to a hesitation to voice concerns because of a lack of self-confidence (Brinsfield, 2003). Also, empowerment through information was highlighted in Nanton’s study in which knowledgeable men questioned doctors. However, this was mainly exhibited among younger men (Nanton & Dale, 2011). Nanton’s study asserted that older men’s silence might have been attributed to their age, vulnerability and their historical and cultural healthcare experiences (Nanton & Dale, 2011). In the current study, a lack of self-confidence was also reported among university-educated men who believed it was not the patients’ place to question doctors, which is illustrated in relation to power (see 7.2.4). Joseph-Edwards (2014) systematic review clearly supports this finding. They highlighted patients’ presumptions of their role inclusive of the belief that the hospital environment is not for asking questions, that asking questions would undermine the physicians’ role and that doctors do not want them to ask questions. Relational silence was also demonstrated in the doctor-patient relationship in which men reported assuming the role of ‘good patient’ by keeping quiet so as not to upset the ceremonial order of the consultation. This will be further discussed in 7.2.4.
Other types of silence highlighted in the current study in relation to suppression of voice and passivity reflect similar concepts in PCa and other studies, as discussed below. The current study highlights how men’s perceptions of providers responsibilities amidst busy clinics, shortage of staff and increasing workload, imposed men’s silences. Their silence was in response to provider silence and in context to avoid contributing further to doctor’s clinical burdens.

7.2.3.3 Silence in relation to suppression of voice

In the current study men and their partners’ experienced suppression of voice whilst interacting with staff. This was categorized as, ‘I couldn’t answer’. This type of silence was mainly related to men’s perceptions of power imbalance in relationships, which is discussed in 7.2.4. Suppression of voice also occurred when men were silenced from communicating with their spouses when they perceived that their spouse did not understand their PCa experiences.

Suppression of voice was reproduced in Sinfield’s study when partners were not invited to ask questions nor invited to participate in consultation with their husbands (Sinfield et al., 2008). In relation to communication between couples with PCa, suppression of voice was echoed as ‘constrained communication’. This reflects the importance of privacy evidenced through their wishes for partners’ not to disclose their cancer diagnosis, or appointments to anyone (Wootten et al., 2014). This highlights the importance of privacy for men. Additionally, silence was captured among couples that avoided discussions that pertained to intimacy (Wootten et al., 2014), and among those in which conversations were controlled (Harden et al., 2002). Underpinning concepts of silence in these aforementioned studies were neither sufficiently explored nor defined. This study demonstrated the impact of cultural beliefs and connections with men’s reticence.

7.2.4 Power and silence

Power is central to the SAACM theory and relates to interaction with healthcare professionals. ‘Power imbalance in health care relationships’ is defined as the belief that power in relationships is asymmetrical with regards to the provider being more superior to the patient based on
knowledge, skills and experience in healthcare (Wilson-Barnett, 1989). SAACM theory proposes that two types of silence exist in relation to power imbalance in healthcare relationships: ceremonial and imposed silence. Ceremonial silence is defined as being silent when interacting with healthcare providers as a means of maintaining order in the clinic. This aspect of silence is based on perceived notions of patient and provider roles in healthcare. This follows Strong’s bureaucratic structure of the provider-patient relationship (Strong, 1979), whereby boundaries are maintained. The patient perceives that silence denotes respect for the providers’ knowledge and expertise and questioning or participating in the consultation may be perceived or interpreted as challenging HCPs authority. The SAACM theory proposes that patient perceptions of asymmetrical power in the provider-patient relationship induce ceremonial silence when interacting with healthcare providers. This is evidenced when patients assume the ‘sick role’ as silent and passive. Imposed silence differs from ceremonial silence in that suppression of voice occurs because of healthcare providers’ behaviours. These relate not only to provider-patient interactions and experiences, but also perceptions and beliefs of the experiences. These refer to but are not limited to the healthcare providers’ greeting, body posture, information shared during consultation, length and nature of consultation, cues, caring aspects, physical examination or touch, interactions with patients and type of relationship. As stated, power is a major concept across all aspects of silence in the current study and relates to men’s perceptions of doctors as powerful and experts and in context with themselves as patients; their interactions with doctors and in relation to patient-provider relationships. Men’s perceptions cause them to defer to doctors, which influences silence.

7.2.4.1 Men’s perceptions of doctors and other HCPs

With regard to men’s perceptions of doctors as powerful beings, men from both islands felt that doctors were equivalent to God in light of their expert knowledge and skills and ability to heal the body. This contributed to ceremonial silence, and mirrors Joseph-Williams et al., (2014) systematic review in which patients were fearful of being perceived by doctors as ‘the difficult patient’ and subsequently the consequences related to these such as substandard care and less attention. The ‘difficult patient’ was described as one who asks questions and offers suggestions in medical decision-making. Patients perceived that verbally communicating with doctors was a sign of disrespect and as such chose to conform to their perceptions of the good patient, which is silent, detached, non-questioning and passive in consultation (Joseph-Williams et al., 2014).
However, the ‘difficult patient’ men assumed in the current study was in context of the busy clinics and providers work-related burdens. Men felt that asking questions and requesting information from doctors during these times will make them appear difficult and not understanding of the work conditions doctors were experiencing.

7.2.4.2 Men’s perceptions of self as patient

Men’s perceptions of themselves as patients’ in the current study was reported as passive, non-verbal and giving control of the consultation over to providers. This contributed to men being voiceless, self-imposed or the suppression of their voice, and perceptions that these characteristics emulated ‘a good patient’. Men’s passivity demonstrated through reciprocal silence was also due to doctors’ reported silence and reflected men’s dissatisfaction and anger. The meanings behind this type of silence resonates with that of an anthropological study which highlighted silence and its role related to feelings of dissatisfaction and to passive resistance as the symbolization of silence for the Japanese (Seltman, 1991).

Men’s perceptions in the current study were also related to uncertainty of what their roles as patients entailed. As such, most men described waiting on their providers to provide information and an invitation to ask questions. As such men reported experiencing long periods of silence, which eventually led to the development of a wall of silence, in which the healthcare provider and the men were protecting themselves from breaking significant news and talking about the state of the situation respectively. This led to men’s frustrations and feelings of emptiness whilst in consultation. This type of silence mirrors awkward silence as highlighted in Back’s study, which denotes extended periods of silence due to uncertainty, distractedness or hostility (Back et al., 2009). The findings concur with that of one anthropology study that highlighted how voice is integral to self-expression among Americans and Europeans and as such extended silence may contribute to feelings of discomfort for these people (Kennedy, 1977). Additionally, the silent wall in the current study echoes a type of silence in self-psychology, which describes ‘silent together’ when both speaker and listener are both silent, that is, when the patient demonstrates ‘analytical silence’ because of perceptions that this is expected in therapy. Equally, the therapist who omits feedback during this time induces further anxiety, confusion and appears inept. Elson purported that ‘silent together’ signifies a breakdown of communication (Elson, 2001).

Foucault talks about silence with regards to the ‘birth of the clinic’ and the way processes are organized in a manner that establishes a power discord with the system taking precedence over
personalization, which corresponds with bureaucratic silence (Foucault, 1975). One study found that doctors perceive silence to be a part of their profession. This encompasses a warning shot that the doctor is about to give bad news about health matters, which may be incurable (Kanzaria & Brook, 2013). This may have contributed to doctors’ silence in the relationship. Apart from psychology and counselling, literature on silence in relation to other health fields is deficient. This study underscores the significance of research in this area.

7.2.4.3 Lack of a personal approach

In the current study men highlighted that doctors’ lack of a personal approach contributed to their reticence and silence. This pertained to the reported non-verbal behaviours of medical staff such as a standing doctor, lack of touch, inclusive of physical examination; eye contact, absence of greeting, and appearing as too busy. This finding was supported by a few studies in which men felt staff was ‘too professional’ and ‘distant’. This lack of a personal approach caused men not to openly communicate their concerns with staff (Milne et al., 2008; Harden et al, 2002; Sinfield et al., 2008). Doctors’ verbal behaviours also influenced men’s silence in the current study and were demonstrated as rushed appointments, use of medical jargon without explanations and speaking too quickly in consultation. The findings highlight that men prefer a more easy-going and friendly style of communication with doctors. However, it highlights the difficulties doctors face towards communicating with men during work-related constraints and the impact of their silences on men’s perceptions of a caring profession.

7.2.4.4 Lack of a trusting relationship

Men’s ability to freely communicate with providers in the face of power was also influenced by a lack of a trusting relationship with doctors as seen in the current study. Some reasons identified for these were consulting with different physicians, and a lack of empathy demonstrated from providers due to the high patient-provider burden and shortage of staff. These made it challenging for men to discuss sensitive concerns such as impotence and emotional distress with physicians. This links with self and masculinity as previously discussed.
The concept of interacting with multiple physicians could be interpreted as communicating with a stranger each time, which affects relationship building. This was highlighted in two separate anthropology studies in which silence denotes unfamiliarity and caution for Western Apaches and Malesian tribe when interacting with strangers (Basso, 1972; Malinowski, 1989).

7.2.4.5 Silence in relation to passivity

In the current study men reported silence in relation to passivity. One major aspect of this type of silence was attributed to power imbalances in provider-patient relationships, in which men perceived that their role as patient was to be ‘passive’ in their interactions with doctors as discussed in 6.5. Another aspect of silence as passivity was captured by the category, ‘I didn’t ask’, and was centred on men’s reciprocal silence. This pertained to a lack of interaction, asking questions or requesting information from HCPs due to their silence demonstrated in consultation. This concept of silence also correlates with power and silence and will be discussed later on (see 6.5). Apart from connections with power, silence in relation to passivity in the current study also relates to men interacting with various providers rather than a sole provider, and a lack of knowledge of the prostate gland, PCa, diagnostic tests, and treatment. This study highlights the types of silences generated among men due to inadequate interactions with the same provider as arising from the shortage of staff and a lack of standardized NHS throughout TT which may have implications for doctor-patient relationship-building.

Silence in relation to passivity mimics Mather’s study in which men failed to question their providers when they received conflicting and confusing information along care pathways for PCa (Mathers et al., 2011). As in the current study, lack of knowledge was also highlighted as contributory to this type of silence (Mathers et al., 2011). This adds new evidence to Ocho and Green (2013) findings, which found cultural beliefs and not knowledge as barriers to PCa screening. However, the population researched in the current study in TT were men diagnosed with PCa unlike the aforementioned study that recruited men from the general public and were underrepresented of men over 60 years of age that reflect higher incidences of PCa according to the National Cancer Registry. The attribute of passivity parallels ineffectual and disengaged silence as highlighted in organizational communication literature. These types of silences relate to the belief that speaking up will not effect change, resulting in disconnect in relationships. This illuminates the experiences of men’s silences in light of the current situation of PCa care in TT.
7.2.4.6 Needed silence

In the current study couples also highlighted that doctors did not pause after giving them the news of cancer or offer an invitation for them to ask questions during consultations. This type of silence called invitational silence in health sciences literature refers to an empathic response that provides time for patients to respond or assimilate information provided (Back et al., 2009), or the silence or pause that occurs before or following an invitation to ask questions (Bristowe & Patrick, 2014). A few participants in the current study stated that periods of silence were experienced whilst interacting with staff at private health systems and specialist oncology departments that portrayed warmth and concern. This was described as calming and serene and enabled men to feel at peace in the midst of their distress. Here, silence reflects calmness, productivity and peacefulness. This reflects compassionate and eloquent silence in health sciences and cancer literature. Researchers found that this facilitated emotional connection and a therapeutic relationship (Bartels, 2014; Bartels et al., 2016). This study underscores the impact of system constraints on Afro-Caribbean men and spouses emotional well-being along routes to diagnosis for PCa.

7.2.5 Antecedents of silence in relation to the SAACM theory

Antecedents are events or attributes that occur prior to the occurrence of a concept as purported by Walker and Avant (2005). With regard to silence, the antecedents that precede silence in the current study reflect men’s social and cognitive elements of self as person. These pertain to hegemonic masculinity norms, lack of knowledge and lay health beliefs and practices, and address the research question, ‘why do men access healthcare services late in TT?’ These antecedents echo silences in health sciences literature and are now discussed.
7.2.5.1 Hegemonic masculinity norms

Hegemonic masculinity norms refer to stereotypes, ideologies and social norms that demonstrate how men should behave (Connell, 2000; 2009; Addis & Mahalik, 2003). Three hegemonic masculinity norms are central to the SAACM theory and denote how the socially constructed nature of men’s gender relates to the illness experience towards inducing silence. These are stoicism, self-reliance and self-concealment.

7.2.5.1.1 Stoicism

Stoicism refers to the perceived notion that men are supposed to bear painful symptoms and distress without disclosure (Seddon, 2005). In the current study most of the men from both islands bore painful symptoms of back, groin and leg pain and difficult urination and emotional distress due to perceptions that stoicism were expected of men. As such, most of the men delayed appraisal and medical help-seeking. Their experiences of a disrupted biography in which debilitating symptoms could no longer be endured, coupled with their inability to work and continue their family role as breadwinner contributed to medical help-seeking behaviours. This study showed that disruptions may not only be experienced in context of the emerging illness or the news of the diagnosis, as purported by Bury (1982). However, it occurs prior to the diagnosis period and extends throughout routes to diagnosis, inclusive of treatment and follow-up care for TT men. The current study also highlighted that Bury’s biographical disruption framework is limited to gendered dimensions. Men sought help at emergency departments throughout TT. Additionally, none of the men opted for counselling when this was offered during the interview. Men in the study made comments suggestive of stoicism such as ‘I am a man, I can deal with this’ and ‘we men are made to handle these things’. The study brings to light masculinity experiences in relation to cultural beliefs of men in both islands of TT.

Several studies concur that those masculine stereotypes such as stoicism is an antecedent occurring prior to the occurrence of silence among men with PCa (Chambers et al., 2017; Ervik & Asplund, 2012; Gray et al., 2002; Wall & Kristjanson, 2005; Wall et al., 2013). Wall and Chambers’ study highlight how the stereotype of the macho image of men contributes to their endurance of distress and delays in seeking support from friends, family and HCPs for health concerns. These stereotypes induce men’s silence through non-disclosure of feelings and emotions (Wall et al., 2013; Chambers et al., 2017). Wall and Kristjanson (2005) found that men’s adoption of a stoic attitude is for the purpose of relieving distress. However, these studies
conducted do not shed light on how men’s masculinity are impacted by their perceptions and experiences of health services, and more specifically in the areas of prostate health in TT.

7.2.5.1.2 Self-reliance

Self-reliance/self-sufficient pertains to man’s dependency on his own resources rather than requesting help from health providers (Leipert & Reutter, 2005). In the current study men utilised self-care practices such as herbs, OTC drugs and self-monitoring of their bodily changes. Others identified how they tried to think and speak positively to themselves to manage distress. Self-reliance was echoed in Wall’s study, in which men utilised positive self-talk to manage the impact of the illness rather than talking to others (Wall et al., 2013). Self-reliance as an antecedent of silence was also reflected in Gray’s and Halbert’s study, in which men chose to stay in control of their experiences and remained silent about their distress so as not to appear needy (Gray et al., 2000a; Halbert et al., 2010). What Gray and Halbert’s study did not shed light on were underlying factors that were contributory to men’s self-reliance. The current study brought to light how masculinity norms such as self-reliance were influenced not only by men’s ‘macho image’ and their cultural beliefs and perceptions but also demonstrated the impact of the high patient demand at cancer centres and experiences of prolonged waiting times, diagnostic and treatment delays and lack of medical insurance and finances, as influencing men’s self-sufficiency. This contributed heavily to men’s self-practices such as self-monitoring, usage of herbs and gravitating to religious instructions.

7.2.5.1.3 Self-concealment

Concealment of vulnerability or self-concealment relates to men’s non-disclosure of the impact of emotions, thoughts and behaviours during the illness experience that may expose helplessness or weakness (Larson & Chastain, 1990). In the current study men conformed to societal norms that the male gender should not display feelings and emotions such as fear, crying or pain. This was also inclusive of men’s accounts of interacting with HCPs, in which they were expected to conceal their emotions and physical distress whilst interacting with staff. As such men highlighted how they withdrew from significant others emotionally, physically and
socially in order to hide their feelings and cope positively during care pathways due to these beliefs. This was also inclusive of not disclosing their feelings to HCPs.

The antecedent of self-concealment in relation to silence mirrors a few PCa studies. In Wall’s study silence was experienced as ‘hiding distress’ and ‘attenuating distress’, in which men concealed their feelings of distress, and utilised strategies to lessen the intensity of their feelings, such as reflecting on good times prior to their diagnosis rather than talking about the present (Wall’s et al., 2013). Chapple and Gray’s study highlighted how men struggled to conceal their emotions so as not to expose their vulnerability (Chapple & Ziebland, 2002; Gray et al., 2000a); and avoid unburdening on spouses (Gray et al., 2000a). Men’s limited disclosure helped them to remain stoic (Gray et al., 2000a). Even though some men stated that they wanted to be open about their feelings in Ervik’s study, they specified that masculine stereotypes existed in which society perceived that men should be silent about their distress. These were highlighted as cancer causes silence and cancer is hush hush. The concept of hegemonic masculinity norms as highlighted in the SAACM theory was also reflected in Ervik’s study in which men felt that talking openly about their health problems was likened to a female affair (Ervik and Asplund, 2012). Withdrawal from significant others and isolation were experienced by men to hide their vulnerability in the face of PCa (Salomo et al., 2016; Appleton et al., 2015; Chambers et al., 2017; Gray et al., 2000a; Krumwiede & Krumwiede, 2012). The current study emphasizes how men’s experiences of silences within health systems add to the burdens men face alone with debilitating symptoms, uncertainty, fear and emotional turmoil of their prognosis.

One interesting finding from the current study was that men highlighted societal stereotypes that existed in TT in which individuals with darker skin tones and those of African descent were expected to bear symptoms in comparison to men of lighter skin tones and those from other ethnic groups. This links back to the colonial period in which lighter skin African workers were kept as indoor slaves and those with darker skin were sent to work in the fields (Pinkney, 2012). As such, lighter skin African people are deemed weaker and less strong than those of darker skin tones. These hegemonic masculinity norms induced non-disclosure of emotional and physical impact of the PCa experience.
The hegemonic masculinity norms of stoicism, self-reliance and self-concealment as antecedents of silence in the SAACM theory underscore the challenges men face when experiencing ill health, which impinges on their experiences of prostate health and in communicating concerns with significant others and with seeking health care.

7.2.5.2 The concept of lack of knowledge in SAACM theory

These refer to men’s lack of knowledge of the asymptomatic nature of early stage and symptoms associated with advanced prostate disease. Most men in the study were not aware of the presence of the prostate gland. This concurs with studies examining men’s experiences of PCa (Anderson et al., 2013; Docherty et al., 2007; Harden et al., 2002; Gray et al., 2000a; Kelsey et al., 2004; Krumwiede & Krumwiede, 2012; Nanton & Dale, 2011; Ervik & Asplund, 2012; Salomo et al., 2016; Sinfield et al., 2008).

7.2.5.3 The concept of lay health beliefs and practices in SAACM theory

These refer to beliefs that exist among non-health professionals towards health and illness that inform decisions and way of life and induce non-reporting of health concerns to health providers. Lay health beliefs and practices pertain to personal, religious, cultural, spiritual and traditional beliefs and practices (Stacey, 1988). Men in the current study from differing socioeconomic backgrounds held lay health beliefs prior to the occurrence of silence. ‘Prostate disease is an old man’s disease’, and ‘one should not see a doctor unless very ill’ were some beliefs highlighted in the current study. Most men in the literature also held cultural beliefs prior to the occurrence of their bodily changes that impinged on appraisal of symptoms and help-seeking actions. Ageing and normality were major beliefs identified in the literature (Anderson et al., 2013; Boehmer et al., 2001a; Docherty et al., 2007; Nanton & Dale, 2011; Jonsson et al., 2010). Other lay beliefs and practices, such as herbal medicine and family traditions were also highlighted in King-Okoye’s systematic review (King-Okoye et al., 2017). There is a dearth of studies that explore beliefs among differing ethnic groups, which can help contextualize meanings of these as it pertains to health.
In relation to practices in the current study, men utilised herbs, consulted with either the pharmacist or the traditional healer prior to the occurrence of silence. According to current literature the role of the traditional healer and the use of herbal medicine has evolved over the last decade in comparison to ancient times (Barnes et al., 2007; Eisenberg et al., 1998). Mainly uneducated people that resided in rural areas from under developed countries consulted with traditional healers for health concerns because of cultural beliefs embedded from ancestral heritage (Waxler-Morrison, 1991; Willcox et al., 2004; Peltzer, 1998). Although traditional healers are primarily cited in the literature as being mainly among African (Hopa et al. 1998) and Asian ethnic populations (Sofowora, 1996), there has been widespread publicity of evidence showing the benefits of usage of herbs and the importance of traditional healing for health problems (Werner, 2014). Additionally, herbs are more affordable for people in poverty-stricken areas in comparison to conventional medicine (Mysorekar, 2013). This has significantly influenced people’s beliefs from other cultures towards preventative healthcare as well as help-seeking for health concerns among educated, uneducated and affluent and non-affluent populations (Gureje et al. 2015). Moreover, health practices have integrated conventional and traditional medicine and considered traditional healers input to facilitate a timely diagnosis and treatment for diseases such as HIV, tuberculosis, cancer and other diseases in certain countries such as Ghana (Kavi et al. 2008), South Africa (Ramgoon et al., 2011), China (Keji & Hao, 2003), Singapore (Courtright et al., 2000) and Uganda (Green, 1995). However, there is a dearth of research that examines the role of the traditional healer towards prostate health and men’s help-seeking experiences. This is critical to unearth facilitators and barriers to care and is further discussed under recommendations for future research.

Additionally, traditional healers are readily available, are the first frontier for treatment and share the same culture and belief systems as the inhabitants (Nattrass, 2005; Winstanley, 2004). The literature highlight reports of effective interpersonal communication such as active listening, use of touch, giving opportunities for asking questions and the provision of information between participants and traditional healers in comparison to experiences of poor doctor-patient relationships. This demonstrates reasons why people prefer to consult with them primarily for health problems (Winstanley, 2004; Labhardt et al., 2010). This may be related to collectivist values or the belief in respect, trust and conduct which are signs of support among people from Asian and the African community (McCrae et al., 1998; Triandis, 2002). Two separate studies conducted in the UK and Cameroon found that traditional healers utilised a
more patient-centred approach with respect to psychosocial issues rather than medical issues and highlighted how openness and personalization that was significant for persons utilising complimentary therapy (Gage et al., 2009). For example, traditional healers asked patients about their opinions and beliefs of the illness experience (Labhardt et al., 2010). Additionally, this may have influenced silence with HCPs on a cultural level for participants, since they may not view clinicians of western medicine as accommodating to traditional medicine. This may have been contributory to participants’ non-disclosure of information to HCPs. In the current study men continued to use herbs during the pre-treatment, diagnosis and treatment pathways of PCa without disclosure to their provider, which impacted compliance to treatment and contributed to treatment delays. This was also a common finding among men in other studies and was connected to fear of the clinicians’ reactions, fear of being judged and perceptions that clinicians should initiate questions regarding the use of herbs (Shelley et al. 2009).

Some of men’s practices were aligned to their religious beliefs that were acquired through instructions from religious leaders, which was highlighted in King-Okoye’s systematic review as significant for certain cultural groups (King-Okoye et al., 2017). This also sanctioned participants’ herbal use for health concerns among men in this study. This resulted in frequent self-management practices and consulting with pharmacists for managing pain and other symptoms, which led to the development of advancing prostatic disease. The belief in demons as being responsible for ill health coupled with faith healing and baptism for the reversal of bodily changes led to delays in appraising symptoms as serious and needing medical attention in the current study. There is considerable evidence highlighting the centrality of religion to help-seeking beliefs, which has impeded and facilitated timely access to primary care services (Conde et al., 2011; Hamrick & Diefenbach, 2006; Holt, 2009; Barwick et al., 2009). For example, a few studies conducted in the UK have shown that participants who regarded their bodies as God’s temple actively engaged in preventative health practices, such as annual DRE and PSA blood test despite their perceptions of the DRE as being associated with homosexuality (Conde et al., 2011; Hamrick, 2006; Holt, 2009). Conversely, men that view conventional medicine as harmful to the body experienced help-seeking and treatment delays for PCa. This was linked to their belief that herbalists have more natural medicine. Even though the literature highlights a positive correlation between an intrinsic locus of control and help-seeking behaviours (Barwick et al., 2009), there is insufficient evidence that explores how religious beliefs influence help-seeking behaviours from this perspective specifically for prostate health. This evidence can be culturally located and serve as a guide to public health messages for prostate health. The belief in
pharmacists as first line administrators have been highlighted in the literature as a major barrier to medical help-seeking among both educated and uneducated people. Men receive advice about pain medications to relieve painful symptoms. However, men are not encouraged to seek further medical help (Schindel et al., 2017; Amoah et al., 2014). This underscores the significance of increasing men’s awareness of pharmacists’ role along care pathways and promoting pharmacists’ involvement towards giving advice to men and encouraging medical help-seeking. This has potential to demote men’s self-management practices and facilitate timely help-seeking at primary care services.

7.2.6 Contributors of silence in relation to the SAACM theory

As discussed, silence heavily influenced men and their partners experiences along their journey to diagnosis and treatment of PCa in TT. Three factors contributed to the occurrence of silence according to the SAACM theory and apply to the effects of health systems. These are uncertainty, lack of awareness and delays in healthcare.

Uncertainty is defined as a state of being uncertain, a lack of understanding or confidence (Oxford dictionary, 2016). With regards to the SAACM theory, uncertainty is one contributor that was influenced through interactions with health systems and occurred due to non-disclosure of information along care pathways. This also pertained to non-disclosure of health concerns to HCPs due to an inability to understand meanings associated with events and outcomes during the appraisal, help-seeking, diagnosis and treatment phases for PCa. The concept of uncertainty as a contributor towards men’s silence was echoed in a few studies in relation to treatment, disease progression and recurrence (Anderson et al., 2013; Cayless et al., 2010; Salomo et al., 2016; Docherty et al., 2007; Harden et al., 2002; Kelsey et al., 2004; Milne et al., 2008; Nanton & Dale, 2011; Ng et al., 2013; Sinfield et al., 2008; Walsh & Hegarty, 2010). The concept of uncertainty as a contributor of silence highlights the role of HCPs towards the provision of information for men and their partners’ empowerment along PCa care pathways.

Lack of awareness was captured in the current study as to being uninformed about the workings of the prostate; bodily changes related to this and symptoms suggestive of PCa; diagnosis, diagnostic tests, treatment and follow-up care and support. It also pertained to non-publicity/advertisement of steps to be taken to report bodily changes and health concerns to healthcare providers and help-seeking channels. Men’s beliefs of the DRE in the current study
in relation to homosexuality was echoed in the literature as mostly relating to masculinity stereotypes, culture and a lack of awareness (Ocho & Green, 2013; Pereira de Paiva, 2011; Romero et al., 2008; Zhang et al., 2015). Lack of awareness of the prostate, symptoms suggestive of PCa, diagnosis and treatment resonate widely in the literature (Berger et al., 2014; Boehmer & Clarke, 2001a; Ervik & Asplund, 2012; Harden et al., 2002, Jonsson et al., 2010; Kelsey et al., 2004; Milne et al., 2008; Sinfield et al., 2008; Smith et al., 2017; Walsh & Hegarty, 2010; Wootten et al, 2014). King-Okoye systematic review highlighted the significance of promoting awareness of PCa within the community, such as the church, which has implications towards minimizing delays in prostate health (King-Okoye et al., 2017).

Men in the current study experienced significant delays in relation to health systems (patient delays were previously described). Delays refer to an interruption in the timely flow of care pathways for PCa (Scott et al. 2013). These were in relation to scheduling appointments, diagnosis, treatment and follow-up care. Reasons highlighted for these were distrust, discrimination, and shortages of staff, lack of personalization, unavailability of drugs, and lack of medical equipment. These findings mirror men’s reports of delays in the medical system along care pathways for PCa (Neal & Allgar, 2005; Berger et al., 2014; Docherty et al., 2007; Stevens et al., 2010; Tran et al., 2015).

7.2.7 Consequences of silence in relation to the SAACM theory

According to the SAACM theory, there are two stages of consequences of silence. These are divided into initial and subsequent stages, demonstrating the occurrence of silence along various aspects of the care pathways for PCa. The initial stages in the current study occurred during the onset of bodily changes. Silence in this context refers to lack of publicity and health promotion regarding information of the workings of the prostate and symptoms related to PCa; help-seeking channels, diagnosis, treatment and support. Being uninformed, unable to voice and recognise and interpret symptoms as needing medical attention and late help-seeking behaviours were initial consequents of silence. These findings were mirrored in the literature across pathways for PCa (Anderson et al., 2013; Nanton & Dale, 2011). In relation to the pre-diagnosis and diagnosis trajectory, some men associated PCa with the colloquial term ‘stoppage of water’ in the community but their knowledge of the disease was limited due to lack of publicity of prostate disease (Nanton & Dale, 2011). Men were not aware of the asymptomatic
presentation of early stage prostate disease (Anderson et al., 2013; Cayless et al., 2010; Ng et al., 2013). Due to lack of awareness of PCa and a lack of knowledge towards interpreting symptoms, men that were symptomatic could not make connections with PCa and were unaware of the significance of these (Anderson et al., 2013, Cayless et al., 2010, Docherty et al., 2007; Sinfield et al., 2008; Walsh & Hegarty, 2010). King-Okoye’s systematic review highlighted how men made connections with their symptoms of back pain, urinary and sexual changes as relating to ageing, normality, infection and transient (King-Okoye et al., 2017).

In the current study subsequent stages of silence occurred during help-seeking, diagnosis, and treatment pathways for PCa. Since men did not have sufficient information towards understanding their bodily changes, feelings of disempowerment developed with time. Non-reporting of health concerns to medical experts resulted in help-seeking delays, advancing PCa and a high symptom burden. This contributed to late diagnosis and poor prognosis. Blame and distrust occurred due to silence experienced when interacting with healthcare professionals. These findings resonate in other studies in which men also experienced blame and distrust as consequences of silence in relation to medical help-seeking, diagnosis and treatment for PCa (Boehmer & Clarke, 2001a; Kelly, 2009; Krumwiede & Krumwiede, 2012; Mathers et al., 2011; Sinfield et al., 2008). This study illuminates the impact that silence has upon men’s emotional wellbeing and progression along care pathways for PCa.

7.2.8 Adaptation and resolution factors of silence in relation to the SAACM theory

The SAACM also highlights adaptation and resolution factors of silence. Adaptation refers to self as manifested through physical, emotional, spiritual and mental adjustment to silence. The physical factors manifest towards self-care. Self-care is any self-initiated human regulatory function (Segall & Goldstein, 1989). In the current study self-care related to men’s self-monitoring of bodily changes, use of OTC medication and herbal use, adherence to advice from non-healthcare providers (these include traditional healers or significant others) and self-led activities for painful and debilitating symptoms. These findings concur with King-Okoye’s systematic review, which highlighted self-monitoring and self-management practices as contributions to men’s appraisal and help-seeking delays (King-Okoye et al., 2017).
In the current study a lack of knowledge and awareness contributed to diagnostic and treatment delays, as men did not seek help in a timely manner. This resulted in physical and mental disconnect from primary care services. Physical disconnect was manifested through self-care activities as highlighted; non-compliance to appointments at public health systems and reported help-seeking at private health systems. These findings were echoed in a few studies in which men experienced disconnect through purchasing healthcare and non-compliance to appointments (Docherty et al., 2007; Sattar et al., 2018).

In the current study mental disconnect was reported as distrust towards HCPs and feelings of abandonment, which resulted in isolation. These findings support other studies that highlighted poor communication as a contribution to perceptions of an uncaring health system (Milne et al., 2008; Nanton & Dale, 2011; Harden et al., 2002; Walsh & Hegarty, 2010; Sattar et al., 2018; Wennick et al., 2017). This led to feelings of distrust and disconnect in healthcare. The current study also highlighted emotional disconnect evidenced as fear and anxiety of health outcomes. Anderson highlighted how a lack of prostate education contributed to increasing anxiety and fear for men along PCa care pathways (Anderson et al., 2013). In the current study physical, mental and emotional disconnect facilitated a spiritual connectedness to God. This was demonstrated through a deepened prayer life, a decision to engage in water baptism, increased church attendance and a stronger belief in God’s ability to restore a healthy body. These findings concur with King-Okoye’s systematic review and other studies in which spirituality was highlighted as significant towards men’s coping mechanisms. These were identified mainly among men from BME groups (King-Okoye et al., 2017; Jonsson et al., 2010; Nanton & Dale, 2011; Ng et al., 2013; Wenger, 2013). This contrasts with one study in which men felt talking to God would contribute to ‘low spirits’ (Ervik & Asplund, 2012).

The resolution factors in the SAACM theory pertain to information, social capital and role of women towards breaking the silence. In the current study a few men received information through reading the Internet, from health care staff and significant others along care pathways. This facilitated empowerment towards recognition of symptoms for a few men as it relates to the prostate and PCa; knowledge that early detection of PCa has a better prognosis than advancing and advanced prostate disease; and an awareness of support systems for men and their families along the trajectory of care. For some men these facilitated timely help-seeking,
alleviated fear and anxiety and compliance to treatment and follow up care. Information as one resolution to silence was mirrored in the literature in which men described feeling empowered sufficiently to question doctors (Kelsey et al., 2004; Nanton & Dale, 2011).

Men and their partners’ social capital were contributory to their knowledge, awareness and information gained throughout PCa pathways. This relates to the network of knowledgeable contacts that are influential with regard to information about various aspects of care pathways (Adlion & Kwon, 2002). The inclusion of shared experiences along trajectory of care also motivated men in the current study towards appraisal, help-seeking, diagnosis and treatment for PCa. This resonates with King-Okoye’s systematic review, which highlighted the role of social contacts towards the provision of information and beliefs related to help-seeking for prostate symptoms (King-Okoye et al., 2017).

In the current study men’s social capital also pertains to the role of female partners and other women towards prostate health. This addresses the research question, ‘What are the beliefs of spouses/partners towards men’s PCa experiences?’. The role of women towards increasing partners’ awareness of early diagnosis of PCa and their involvement in prostate health in TT were demonstrated in the current study.

Women tried to smoothen the journey for their partners when faced with barriers to care, such as reports of silence from HCPs and uncertainty towards men’s diagnosis and treatment. Their experiences of provider silence compounded the shortage of staff and overcrowding experienced at cancer centres in TT. These contributed to women’s involvement in research via the Internet, books including their contact with other providers in TT and internationally. These strategies were influential towards increasing partners’ awareness of symptoms being connected to PCa. Their roles were highlighted in the current study as requesting and utilising information in relation to symptom recognition and interpretation, medical help-seeking, adherence to appointments, active engagement in consultations, and medical decision-making. With regard to diagnosis, female partners facilitated diagnosis of PCa by ensuring that biopsy samples were sent to cytology. Men’s accounts of women’s role towards treatment and follow-up care were mainly in relation towards gaining information about various modalities and side effects; and motivation and emotional support. A major role highlighted in the current study was in relation to being vocal in consultations. For example, some men that questioned doctors in Kelsey’s study highlighted not receiving answers (Kelsey et al., 2004) as experienced in the
current study. However, women in the current study followed through with consistent questioning and requesting information, which were instrumental towards breaking the silence among men in TT. Other roles of women in the current study were reflected widely in the literature, as researchers, health monitors, supporters and information seekers (Arrington et al., 2005; Boehmer & Clarke, 2001a, 2001b; George & Fleming, 2004; Gray et al., 2000a, 2000b; Madjar et al., 2007; Maliski et al., 2001; Zhu et al., 2012). This study illuminated the significance of women towards early symptom recognition and PCa detection, early diagnosis and timely treatment.

7.2.9 Differences in experiences within the two islands of TT

There were unique differences in experiences among participants from both islands. Here, I answer the research question, ‘What are the differences between the experiences of men and their partners in the two islands of TT?’ The differences relate to men’s perceptions of their roles and the roles of their partners; more men being asymptomatic and at early stages of PCa; usage of herbs and shortage of skilled doctors and scarcity of diagnostic equipment and treatment availability.

Although men from both islands shared similar experiences as discussed in relation to the SAACM theory, men from Tobago were more likely to conceal symptoms from their wives. This was due to their perceptions of a man’s role as breadwinner and provider for their families and women as domestic workers. Underlying factors were common to both groups of men from TT, such as stoicism, resilience and concealment of vulnerability. However, it was noted that Tobago men were more inclined to protect their body image in relation to being able to perform and contribute financially to the family. This may have been associated with more men in Tobago being breadwinners than Trinidad men. Women also functioned as breadwinners, thus sharing the financial responsibilities. This may have influenced Trinidad women to be more proactive as ‘silent breakers’ towards requesting information about their spouses’ health and engaging in questioning providers.

The findings also captured Tobago men’s accounts of participating in prostate programmes whilst in asymptomatic stages of PCa. This may have been related to the availability of screening
programmes that are in Tobago and the absence of these in Trinidad. Hence there were a greater representation of Tobago men’s experiences of involvement in screening programmes unlike Trinidad men and accounts of blame and distrust were made more visible amongst the Tobago group. These experiences were mainly due to their proactive role towards early screening for PCa and their engagement with providers whom they perceived would diagnose and treat PCa.

The use of herbs was more common among Tobago men. One main contributory factor was the shortage of specialist doctors and men’s report of shared specialist doctors with that of Trinidad. These coupled with the scarcity of diagnostic equipment and treatment availability caused men to utilize herbs with the hope of receiving healing. Most Tobago men spoke of travelling to Trinidad to access care through one of the major cancer centres, thus increasing their financial burden. Although Trinidad men had access to centres throughout Trinidad, they were still faced with overcrowding at centres, long waiting times and shortage of staff; however, they accessed care at these Trinidad facilities.

7.3 Reflections on undertaking the research study

7.3.1 Reflexivity in grounded theory

Reflexivity is a critical part of the research process. Reflexivity is defined as the process by which the researcher recognizes constructs that may implicitly and explicitly influence the research process (Guba & Lincoln, 2005; Adkins, 2002). Straussian GT methodology advocates reflexivity as a tool to examine the researchers’ impact, presence and perspectives. This enables rich insight into participants’ responses by allowing the researcher to maintain her preconceived biases, assumptions, beliefs and perceptions separate from that of the participants’ contributions to the research (Finlay, 2002; Corbin & Strauss, 2008).

Reflexivity was achieved through the use of memo-writing and a research diary. I did not use bracketing, which was previously discussed in 3.3.1.1 as one research technique of phenomenology. Straussian GT advocates acknowledgement of researcher biases and cultural
beliefs through the use of a research diary (Strauss & Corbin, 1998). I kept a research diary at the beginning of the research process (2014-2018), which kept my self-reflections for the trajectory of the study (see PhD extracts later in this section.) The research diary helped me to obtain equilibrium by enabling transparency with regard to the researcher’s position and that of the data including methodological and theoretical decisions (Arber, 2006), thus allowing me to maintain a critical perspective of the data (Richards, 2003). According to Alvesson and Skolberg (2009), there are four levels of reflexivity. The first level concerns the empirical data collected with regards to the researcher’s influences on the design, data collection and gathering processes. The second level pertains to researcher engagement and analysis of data in examining how pre-conceived notions or biases may affect this. The third level clarifies the political context such as the power relationships on the data collection and analysis. And the fourth level relates to how language is used to represent participants’ contributions. My background as a cancer specialist nurse and lecturer in cancer care could have affected the aforementioned research processes, such as the empirical findings, researcher-engagement and analysis of data. My experiences of conducting qualitative research were helpful towards maintaining my composure and displaying empathy during these interviews. This facilitated rich data to be collected during interviews as participants reported feeling relaxed and at ease to share their stories. I had to engage in emotional labour after listening to participants’ accounts of disturbing stories during their journey and observing them in distress whilst sharing these with me. This enabled me to keep my personal feelings about participants stories separate to that of the analysis and interpretation of data. The use of current and relevant literature, supervisory expert guidance and the use of reflexivity throughout the research trajectory facilitated transparency of the research process. These enabled objectivity towards recruitment, conduct of interviews, data collection, researcher engagement and analysis of data. Even though this model was useful towards guiding the novice researcher’s approach, it lacked how to practice emotional reflexivity. This has been found to be neglected when doing research (Allan & Arber, 2018). Emotional reflexivity helps researchers deal with painful topics and feelings that accompany health and social care research process. The research diary also enabled me to manage and process emotions developed when interacting with research participants for this study. My reflections of being in the field are described in the next section pertaining to my research identity, recruitment, professional boundaries whilst interacting with participants and conflicts experienced.
7.3.2 Use of my researcher-self versus my professional self

My experiences of access to research sites in TT differed in relation to my use of researcher-self versus professional self. Allan and Arber (2018) highlight the complexities surrounding the researcher’s identity in the conduct of research. They identified that having multiple identities can be problematic and cause a blur to professional boundaries during the research process. Reputation was identified as a key construct when engaging in more than one role in the conduct of research (Allan & Arber, 2018).

I had difficulties accessing the research site in Tobago through gatekeepers. I learned that this was due to my researcher identity as an outsider in the field, which concerned my reputation as highlighted by Allan and Arber (2018). This experience exposed my multiple identities in the research field apart from my researcher identity (see Figure 13). Firstly, I am a born Trinidadian and may be seen as an outsider by Tobago participants and an insider by Trinidad participants. Secondly, I am a Black Afro Caribbean with a comprehensive and shared understanding of the culture and life of the people of TT. This makes me an insider with regard to understanding the language, food, religious beliefs and practices of the people. Thirdly, I am a Christian. This identity may be perceived as both insider and outsider depending on the religious identity of the research participants. Fourthly, I am a female (woman, wife, and mother). This may be treated as an outsider for some men who may not want to be interviewed by a female. This identity was taken into consideration by my supervisors and me. We made provisions for this by having a male researcher (medical social worker) on standby. However, no one requested this. Fifthly, I am a cancer specialist nurse, lecturer and programme administrator who brings to the field a wealth of knowledge, experience and personal and professional biases. Although most of my formal training was done internationally, my position makes me an insider with regards to my professional status in Trinidad. My researcher identity: I had chosen to present myself as a researcher from the University of Surrey for three reasons. Firstly, I felt that this position would enable both the gatekeepers and research participants to see me in the capacity of a neutral person collecting data about participants’ experiences. Secondly, I felt that being a born-Trinidadian, knowledge of this might have influenced Tobago participants’ decision to share their experiences. And thirdly, I perceived that this position would enable me as the researcher to maintain my boundaries to that of my professional self for the entire study. See Appendix 21 for an excerpt from my research log.
7.3.3 Physical structure of research sites

The oncology staff provided me with a large room for conducting interviews with Tobago participants, which enabled me to sort out light healthy refreshments for them (fish pies, tea/coffee, and salads). The centres in Tobago were very quiet with about 10-15 men. There were a few posters with information about the administration of chemotherapy, screening for prostate, cervical and ovarian cancer. I did not observe the research poster advertised at any of the centres. In Trinidad the centres were extensive, very busy and overpopulated. The rooms assigned to me were quite small. As such, I could not provide refreshments for the participants. All the benches were occupied, and some people had to stand in the corridors whilst waiting to be seen by HCPs. Wives accompanied the men to their clinic appointments. I observed the
research fliers advertised. The bulletin boards were advertised with information about female cancers. I did not see any PCa information or advertisements other than the research fliers.

7.3.4 Amendments to interview guide

I noticed some men hesitated with the opening question, ‘Can you share your experiences when you first noticed something was wrong?’ These men were more focused on their co-morbidities or previous illnesses or hospitalizations that were not related to their prostate experiences. One example of this was a man’s account of a motor vehicular accident (MVA) he was involved in. However, I allowed the conversations to flow naturally as some men discovered a high PSA during routine examinations as with the man involved in the MVA. I asked specific questions based on the information given to gain insight into men’s prostate experiences. Subsequently, with the help of my supervisors I had to change this to ‘Tell me your story as to how you came to where you are now’ for the Trinidad men. Some men were not aware that they were diagnosed with PCa or being treated for this. Access to the patient database gave me insight about this. I did not experience interruptions as the oncology nurses allocated the men to the room for interviews.

7.3.5 Interacting with participants

In Tobago, one wife accompanied her husband to the interview. I noticed that most of the men asked me where I was from before signing the consent form. I was honest in telling them that I was from Trinidad and doing my PhD research through the University of Surrey as in the PIS. This experience made me aware that I should have stated that I was from Trinidad in the PIS. My cultural self as an insider was highlighted when the men stated, ‘I am happy you are one of us’ and ‘this is good that you are helping your people’, before the interview started. I realized it was important to let the men know where I was from as I was seen as an outsider when I told them that I was from the University of Surrey. As such, I stated this during self-introduction with each participant before conducting the interview. This information brought comfort to the men in sharing information about their experiences.

Conversely, Trinidad men requested their wives be present during the interviews and vice versa. My introduction as a Trinidadians conducting research facilitated rapport and trust towards
participants’ sharing of information. I noticed that most of the women were breadwinners from the demographic information. I did not have the assistance of staff allocating men to the room as in Tobago. Due to this, I experienced multiple interruptions during the interviews. These were by other participants that desired to participate, HCPs and relatives of research participants. As such some interviews were shorter in duration (40 minutes) than those of Tobago. It was agreed by my supervisors to include these interviews as the amended interview question, ‘Tell me your story as to how you came to where you are now’ enabled experiences shared to be specific to PCa. I still asked questions relating to previous hospitalizations and illness experiences to capture similarities and differences of men’s experiences. Similar to Tobago men, participants were not aware of their diagnosis. My supervisors and I agreed that my approach should not be through the database as with the Tobago study. As such, my position was neutral with regard to knowledge of men’s PCa diagnosis and staging. However, common themes were elicited from the data collected and theoretical saturation was achieved.

7.3.6 Conflicts experienced

I experienced internal conflict about my knowledge of men’s PCa diagnosis during the interviews in Tobago. This arose when men were not aware of this and was uncertain about the symptoms experienced. Additionally, some men were receiving chemotherapy and were not knowledgeable of this. The issue of distance when conducting research has been highlighted as important for researchers occupying dual roles (practitioner/researcher), especially when tensions occur internally through emotions or externally at the physical research site (Allan & Arber, 2018). For me, it was initially difficult to manage boundaries when it concerned men’s desire to know causative factors behind their symptoms. I became sensitive to their concerns especially with my professional knowledge that these were suggestive of metastatic prostate disease. Cooper (2012) highlights how maintaining one’s balance in boundaries can either move forward into one or fall back into another. I had to remind myself of my role as a researcher towards collecting data and keep my professional self, separate from this. Allan and Arber (2018) recommend four strategies for practicing reflexivity in the field before, during and after fieldwork. These are: documenting feelings and emotions during the trajectory of the research in a research diary, having a good support inclusive of both informal and supervisory support.
and self-care strategies such as debriefing, relaxation techniques and counseling. My emotional conflict arising from knowing men’s diagnosis was resolved through constant contact and support from my supervisors. This was also facilitated through discussions and reading of fieldwork entries. Subsequently, it was agreed that access to patients would be from the clinics and not through the database for Trinidad men.

Similarly, at the Trinidad research site, I experienced conflict with a consultant urologist who informed me that he was not comfortable with me conducting research at the department. His disapproval was in relation to my professional self. I communicated this with the top managers, who reminded me that I had approval from them to conduct the study and that the consultant worked for them and not vice versa. This was successfully resolved towards me having access to patients. However, I felt mentally uncomfortable conducting interviews there, as my interview room was opposite his. Since the clinics were quite busy, I could not obtain another room to conduct my interviews. In order to resolve this, I made enquiries as to the days the consultant worked and decided to interview patients on his off days. I felt that this decision for a ‘time-out’ (Allan & Arber, 2018) was a useful approach towards conflict resolution, as I was successfully able to interview participants thereafter.

7.3.7 Contributions of this study to empirical and theoretical literature and models of care

This study has made several contributions to PCa literature, men’s health literature and empirical theoretical understandings and models of care for PCa. Table 19 highlights these contributions. These are discussed under the headings: contributions to gaps in empirical literature, contributions to gaps in theoretical literature and contributions to models of care.

7.3.7.1 Contributions to gaps in empirical literature

This study provides unique insight into barriers and facilitators of prostate care specifically for Afro-Caribbean men in TT, which may be representative of experiences of similar ethnic groups
of men. These barriers were illuminated through this study as lack of knowledge of the prostate gland, PCa and lack of awareness of the need to seek help for symptoms experienced.
| Current state of phenomena in relation to PCa literature, empirical and theoretical gaps, contributions to research and recommendations |
|------------------|---------------------------------------------|---------------------------------------------|---------------------------------------------|
| **What is already known about men and partners experiences of PCa?** | BME men are at a higher risk of developing PCa; higher risk of deaths from PCa | BME men experience delays in seeking help for prostate symptoms; and experience late presentation of PCa | There is evidence that supports a general lack of knowledge of PCa screening, asymptomatic nature of early stage PCa and symptoms suggestive of advanced PCa in men | There are reports of discrimination, perceptions of bias in treatment and distrust among BME men and men from lower socioeconomic backgrounds; the importance of social capital as a facilitator of care has been documented |
| **What is already known about TT men and partners’ experiences of PCa?** | One study that conducted interviews among key stakeholders and the general public 19-60 about their perceptions of PCa screening. | No current research in TT has looked at partners experiences of PCa |
| **Gaps identified in empirical literature** | There is a lack of empirical studies that examines men’s beliefs and meanings related to interpretation of prostate symptoms and meanings behind men’s help-seeking decisions, inclusive of barriers to prostate care in the literature. | There is dearth of research that explores partners roles towards prostate health |
| **Gaps identified in theoretical literature** | Burry’s (1982) theory of biographical disruption lacks a holistic view of men’s experiences of PCa pre-diagnosis and beyond diagnosis and treatment for this disease. His framework is also narrow from the perspectives of relationships, gendered dimensions and psychological perspectives. | Radley’s (1994) illness representations offer a limited scope from a masculinity frame of reference. | The masculinity theories (Connell, 1987, 2005; Kelly, 2004, 2009) examined do not provide a greater insight into how men’s cultural beliefs and experiences impinge on their PCa experiences. |
| **How this study contributes to gaps in empirical literature** | It contributes to PCa literature through highlighting barriers to PCa unique to Afro-Caribbean men in TT. | It identifies variations of beliefs and perceptions towards appraisal, help-seeking, diagnosis and treatment for men with PCa in TT. | It strengthens men’s health literature on how cultural beliefs impinge on their experiences of masculinity in context of routes to diagnosis for PCa in TT. | This study highlights the role of Afro-Caribbean partners (women) towards prostate health in TT |
| **How this study contributes to gaps in theoretical literature** | The SAACM theory illustrates the unique theoretical relationships of masculinity, lay beliefs and culture and symptoms towards a comprehensive understanding of men’s experiences of PCa in TT. | The SAACM theory provides unique insight into how types of silences occur along routes to diagnosis and impact on men’s emotional well-being, prognosis and quality of life for PCa. |
| **What this study highlights as key considerations for further research?** | Afro-Caribbean men and partners experiences of PCa in TT within prostate research programmes and private health sectors to gain a more comprehensive insight into other barriers and facilitators to prostate care in TT. | Health care providers (public and private) experiences of prostate health in TT along routes to diagnosis and treatment will contextualize issues within health care systems and enable a broader perspective from the current research findings. | Traditional healers and herbalists’ perceptions and experiences of PCa in TT. This will highlight the roles they play towards PCa and how they can be utilized to support prostate healthcare in TT. | Pharmacists/pharmacy staff experiences and roles towards PCa in TT. This will unearth their experiences of the general public; their roles towards symptom recognition and medical help-seeking. |
| **The way forward for this research and recommendations** | Meeting with key stakeholders to discuss findings; publish findings in high impact journals. | Provide executive summaries to RHAs; Discuss public health initiatives for TT in relation to PCa. | Examine Government’s considerations of training of advanced nursing practitioners and clinical nursing specialists. | Increasing awareness of PCa via media and health promotion activities within health care institutions and communities. |

Table 19 shows study contributions and recommendations

The study also offers a comprehensive perspective on how men’s beliefs and perceptions impinge on the appraisal process and help-seeking actions for PCa symptoms. This was reflected through the various representations of ethnicities within the twin isle, levels of socioeconomic
backgrounds and geographical locations. The findings of the current study also strengthen men’s health literature as it emphasises how cultural beliefs play an important role towards masculinity as it relates to their experiences of routes to diagnosis for PCa. This was evident in relation to men’s roles, their relationships with HCPs and wives, and the impact of health system constraints on men’s stoicism, self-reliance and self-concealment. The study also contributes towards roles TT women play towards prostate health and their potential functions towards symptom recognition. Women’s beliefs of their spouses’ experiences of PCa and engagement with HCPs contribute to new knowledge in PCa literature.

7.3.7.2 Contributions to gaps in theoretical literature and models to care

The SAACM theory illustrates relationships between lay beliefs, culture and symptoms and masculinity as significant to having a wide understanding of men’s experiences of PCa. It offers insight into types of silences that occur along routes to diagnosis for PCa and the processes that invoke these and impact on men’s’ emotional well-being, prognosis and quality of life. The SAACM enables various representations of beliefs and perceptions from a cultural and ethnic perspective to be unearth. It also calls attention to complexities involving men’s prostate health and underscores the influences of cultural beliefs on men’s experiences. Key considerations highlighted in the study and the way forward is discussed in 7.3. The findings highlight a need to explore cultural beliefs and aspects of masculinity as it relates to Andersen’s model of pathways (Walter et al., 2012). Afro-Caribbean men accounts of their experiences contextualize pathways of care to their lay beliefs, culture and symptoms, and masculinity, which are key considerations for future research.

7.3.8 Evaluating the theory of silence among Afro-Caribbean men

The SAACM theory was evaluated in accordance to Straussian grounded theory criteria. This follows three main evaluative steps, seven conditions, ten general and thirteen specific criteria as identified by Corbin and Strauss (2008)
7.3.8.1 Strengths of the theory

The strengths of the SAACM theory are discussed in relation to Strauss and Corbin’s (2008) seven conditions and ten general criteria. The first criterion for evaluating the strengths of the theory is in relation to its credibility. This emphasizes sufficient detail and descriptions of the theory for readers. The SAACM has been adequately described, providing readers with participants’ accounts of antecedents, contributors, barriers, consequences, adaptation and resolution to silence. The second criterion relates to providing evidence of data collection and data analysis procedures. Interviews were conducted with 51 men and 16 partners from TT. This was also inclusive of a representation of shared experiences and multiple comparison groups, such as variations between research participants of the two islands and negative cases, thus avoiding selective reporting bias. The third criterion refers to a specification of the kinds of data that informed interpretations. The types of data (interviews and observations), inclusive of current and relevant literature, principles of grounded theory (see chapter 6) and memos (theoretical, operational and code notes) were sufficiently described. These showed that the theory is grounded in the data thus adding to its credibility. The fourth criterion highlights the applicability of the theory in relation to fit, being readily understandable among both lay and professional audiences and tailored for diverse populations and situations.

The SAACM theory describes Afro Caribbean men and their partners’ PCa experiences in TT. This theory highlights their beliefs, perceptions, cultural settings inclusive of religious and traditional practices, and behaviours in light of PCa experiences. The problems described have their foundation in political, historical and social conditions that give rise to these social processes. The detailed outline of the theory in relation to the literature provides clear understanding to varied audiences. Additionally, this theory can be adapted to other situations and populations, such as Black and Afro Caribbean men from other geographical locations; as well as with other types of cancers and range of illness behaviours. And finally, the theory should promote change. The SAACM theory has implications for public health advancement, policy development, health training and education. These are discussed in detail in 7.4.

In addition to these three criteria, Corbin and Strauss (2008) also specified an evaluation of the credibility of theory building research through thirteen additional criteria. These explore sampling, categories’ generation, relationships and variations inclusive of negative case analysis,
conditions and consequences, process, significance of theoretical findings and relevance and usefulness to social and professional audiences.

7.3.8.2 Limitations of the theory

Some limitations identified were recruitment of participants, type and location of data collection and the representation of data extracts. The sample may not have been a clear representation of men from both public and private health systems. Interviewing men from private health systems may have enabled me to get a better representation of men with early stage PCa and more men that participated in clinical trials. Also, the use of focus group interviews for women may not have been appropriate as men were not happy for them to share their experiences in this forum. Semi-structured interviews may have been a better approach for all participating partners. Data extracts reflected in the findings' chapters were not representative of all participants, which could influence selective reporting bias. However, key accounts of silence and deviant cases representative of all participants can be seen in Appendix 23. The findings of this study cannot be generalized to the entire population of TT. However, it gives insight into men and partners’ experiences of PCa that may be similar to other men along routes to diagnosis and can be transferable to similar ethnic and cultural groups.

7.4 Implications for public health and policy

The findings of this study have shown significant implications towards public health, policy-making and training and education for prostate health targeting Afro-Caribbean men and black men in general. These will be discussed under three headings: public health promotion, policy-making and training and education.

7.4.1 Public health promotion

The findings highlight poor awareness and lack of knowledge of the prostate gland, the insidious nature of early stage PCa, causes and risk factors of PCa, symptoms of advanced PCa and PCa screening. There is a need for public health promotion and media awareness of these
aforementioned areas in TT. This is discussed under three headings: public health messages, training and education, and other recommendations for further research.

7.4.1.1 Public health messages

The findings showed how men and partners’ cultural settings influenced their beliefs, perceptions, traditions and practices towards men’s prostate health. Their cultural settings were manifested through their religious beliefs, the roles of religious leaders and traditional healers and herbalists and use of herbal medicine. Public health messages can be located within these various cultural settings throughout TT by targeting these leaders (THs, herbalist, pastors, priests) towards creating awareness of prostate health and PCa. These can take the form of blended meetings inclusive of stakeholders, HCPs, the public (both men and partners), and PCa survivors. Discussions can be centred on the importance of early diagnosis and treatment of PCa, efficacy of herbal and conventional medicine for PCa, side effects and PCa screening.

Awareness of PCa can be promoted via churches, barbershops, community centres, gyms and other community organisations (public and private). This can be done through collaboration with TTCS. The MOH can be contacted to implement television and radio programmes specific to discussions around the DRE, PSA test and the prostate gland and symptoms of PCa as well as health services men can engage with for information, guidance and help-seeking. This can facilitate the public’s awareness of PCa and services that provide screening, treatment and education.

7.4.1.2 Policy-making

The findings of the study have given insight into barriers and facilitators of PCa care. This can be useful towards policy making for public health and cancer care throughout TT. Target groups, such as the health board of each Regional Health Authority, policy makers, stakeholders and health care providers. This includes discussions around the current health policy for PCa and the 2020 National strategic plan.
7.4.1.3 Training and education

The SAACM theory showed how research participants’ accounts of silence among healthcare providers provoked anxiety, fear, distrust, frustrations and isolation for men from both islands of TT. The significance of effective therapeutic doctor-patient communication along PCA care pathways and involvement of partners in diagnosis, treatment and follow-up care was illuminated in this study. This calls into focus the need for communication training and education of staff in cancer care towards truth telling, breaking bad news, producing a comfortable environment and utilising effective communication strategies along care pathways. Posters pertaining to prostate health can be done and placed within prostate clinics (urology and oncology units) throughout TT. This has potential towards increasing awareness among both men and their partners at clinics and units. Distribution of leaflets to the general public can sensitize individuals about the presence of the prostate gland, DRE and PSA testing, prostate symptoms and PCA; and diagnosis and treatment of the disease.

7.4.2 Other recommendations for further research

In addition to the public health promotion strategies, messages and training and education, other recommendations are discussed in relation to nudge techniques, use of PCA application software and prostate radar tool and support groups for partners.

7.4.2.1 Nudge techniques

The nudge theory introduced by Thaler and Sunstein (2008) has affected policy makers worldwide (Whitehead, 2014; Voyser, 2015). Nudge techniques are ways to influence individuals’ behaviours towards making responsible, healthy choices. Labelled as “libertarian paternalism”, these techniques utilize manipulation whilst enabling freedom (Methven & Caskey, 2014). These have been said to lower cost whilst promoting responsible behaviours. Physical targets are utilised that influences individuals’ perceptions (Bonell et al., 2011). Some examples are arranging nutritious foods on supermarket shelves at eye-level or utilising smaller serving utensils to influence perceptions towards healthy eating (Mill, 2007). Some other uses of nudge therapy specifically for PCA have been towards shared medical decision-making in clinical
consultations (Aggarwal et al., 2014). This principle can be applied by placing decision aids for PCa screening within barber shops, churches, and throughout communities within TT to promote PCa screening and annual health check-up for men from the general public.

7.4.2.2 Use of PCa software application, tools and support groups

A PCa software application specific to the cultural settings of TT can be utilised towards creating awareness of the prostate gland, early and advanced stages of PCa, screening, diagnosis and treatment. This can be done through health communities within TT and each Regional Health Authority to target both asymptomatic and symptomatic men along various care pathways for PCa. The findings of the current study illuminated the roles of partners towards appraisal, help-seeking, decision-making, PCa diagnosis and treatment. The prostate radar tool has been used in the USA to help women identify symptoms of PCa (Prostate Healthcare New York, 2013). This tool can be evaluated for its feasibility among women in TT towards early PCa detection. Women in TT can serve as advocates and can be trained through educational programmes to identify high risk groups and possible prostate problems that men may be experiencing. An adapted version of the radar tool can serve as an intervention tool, in that women can highlight possible prostate problems as ‘red-flags’, which can motivate men to seek healthcare. This can contribute significantly to health care in Trinidad and Tobago in the areas of Education and Health, including health promotion which are two critical priority areas identified by the Interim Development List of the UK Department for International Development (DFID) and will strengthen The Seven (7) Interconnected Development Pillars of the country. The current findings highlight the significance of support groups for both men and their partners along the trajectory of care for PCa. This has implications towards coping and support and can also be utilised as a form of learning, teaching and communication about PCa diagnosis, treatment and follow-up care.

7.4.2.3 The way forward: Dissemination plan

Preliminary findings of the current study were presented at conferences both locally (UK) and internationally. The findings of this study will be disseminated via various channels. Firstly, these will be shared with the current research participants that indicate interest. Secondly, as this project was part of the Development Needs Sector for TT, I will provide executive summaries and present findings at each Regional Health Authority, inclusive of the Ministry of Health. This
will inform health providers’ knowledge, public health messages and implementation of prostate health-related policies, education and training. Thirdly, I will present the substantive theory of silence among Afro Caribbean men at both national, regional and international conferences and seminars. These findings will be published in peer-reviewed journals that would highlight barriers and facilitators to prostate health among Afro-Caribbean men and the wider BME communities diagnosed with PCa.

7.5 Conclusion

The purpose of this study was to examine the experiences of men newly diagnosed with PCa and their partners’ in TT using Straussian grounded theory approach. Data collected from 51 men newly diagnosed with PCa and 16 partners of these men from both islands generated the categories of ‘Disrupting the self’, ‘Disconnected to health services’, The wall of silence’, ‘Blame and distrust’ and ‘Breaking the silence’. Bury’s (1982) theory of biographical disruption, Radley’s (1994) theory of illness representation and masculinity theories purported by Connell (2005) and Kelly (2004) have been utilised to explain men and their partners experiences along routes to diagnosis of PCa in TT. The core category, ‘Silence among Afro Caribbean men’ represented how men and their partners journey through diagnosis and treatment for PCa in TT. The study showed that silence exists along PCa care pathways that influenced men and partners’ appraisal of symptoms, help-seeking behaviours, and diagnosis and treatment decisions. The theory of silence (SAACM) described barriers and facilitators, inclusive of varied conditions, relationships and contexts, consequences, resolution and adaptation.

This study has contributed new knowledge to PCa studies, public health and specifically pathways to treatment. It first calls to attention the importance of examining routes to diagnosis for PCa to identify men’s beliefs and impact on appraisal of symptoms and decisions to seek medical help. It also emphasizes that hegemonic masculinity norms, such as stoicism, resilience and concealment of emotions; lack of awareness of PCa and lay health beliefs and practices influences men’s high symptom burden, late presentation and emergency admission of symptoms, poor prognosis and increasing PCa mortality rates among men in TT. This study challenges Andersen’s revised model of pathways to treatment (Walter et al., 2012). It asserts that culture, inclusive of traditional and religious beliefs and practices are crucial to understanding facilitators and barriers to care especially for Black men who value collectivism.
as part of their racial identity (Carson, 2009). It has also contributed to research about men’s health. It draws attention to the consequences of silences among men and in response to health care providers, which has contributed to delays along routes to diagnosis, blame and distrust, mistrust and perceptions of an uncaring and exploitive health system. The study identifies how women can be utilised in symptom recognition, appraisal of symptoms and the motivation of men to seek help early for their prostate health. This has implications towards public health messages, policy development, and training and education in TT. Additionally, this theory has potential to be useful towards similar groups of men in diverse geographical locations, and towards political and social audiences.
REFERENCES


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O'Callaghan C, Dryden T, Hyatt A, Brooker J, Burney S, Wootten A et al. (2014). 'What is this active surveillance thing?' Men's and partners' reactions to treatment decision making for prostate cancer when active surveillance is the recommended treatment option. *Psycho-Oncology, 23* (12), 1391–1398.


UK National Screening Committee (NSC). The UK NSC recommendation on Prostate cancer screening/PSA testing in men over the age of 50. Retrieve from https://legacyscreening.phe.org.uk/prostatecancer.


APPENDICES
Appendix 1: Inclusion criteria for SR

<table>
<thead>
<tr>
<th>Inclusion criteria</th>
<th>Exclusion criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>Studies conducted 2004-2017</td>
<td>Studies conducted prior to 2004</td>
</tr>
<tr>
<td>Men from all ethnic groups and nationalities with self-reported beliefs related to symptom (s) of prostate cancer, including BPH and prostatitis</td>
<td>Men with other cancers, partners and health professionals beliefs</td>
</tr>
<tr>
<td>Studies with available abstracts</td>
<td>Studies with no abstracts</td>
</tr>
<tr>
<td>Studies in English Language</td>
<td>Studies in non-English Language</td>
</tr>
</tbody>
</table>
## Appendix 2: List of studies included for SR

<table>
<thead>
<tr>
<th>Author/year/country</th>
<th>Participants characteristics /sample size</th>
<th>Methods and Analysis</th>
<th>Relevant findings</th>
<th>Interpretation</th>
<th>Help-seeking</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>QUALITATIVE STUDIES</strong></td>
<td></td>
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<tr>
<td>Anderson et al., 2013 UK Quality = GOOD</td>
<td>7 African and Afro-Caribbean men diagnosed with PCa; 50 years and older</td>
<td>An exploratory qualitative study: phenomenological approach utilizing face-to-face interviews. Braun and Clarke’s thematic conceptual analytical framework</td>
<td>‘Sexual effects’ (p. 1304) ‘The only thing I felt was maybe, it will affect my sexual life completely, and my wife being younger than me [laughs]… maybe she would find her enjoyment elsewhere… So that made me a bit scared and worried’</td>
<td>It will affect sexual life completely</td>
<td>Scared that loss of sexual functioning will affect relationships</td>
</tr>
<tr>
<td>Blocker et al., 2006 USA Quality = FAIR</td>
<td>14 African American men from the general public; not diagnosed with PCa (Only findings of men included)</td>
<td>Gender-specific focus groups with men and women from two (2) churches Thematic analysis</td>
<td>‘Decreasing urine stream’ (p. 1291) ‘You know at work, sometimes, I'm under a lot of stress ... and when I go to the bathroom, when I urinate, I watch my urine stream. I can tell when I'm in stressful situations because it decreases my urine stream. And that means that something is affecting my prostate’</td>
<td>Stressful situations can cause urinary changes Knowledge Something is affecting my prostate</td>
<td>Need to monitor for continual changes in urine stream before consulting with HCP Knowledge and Experiences Self-monitoring changes</td>
</tr>
<tr>
<td>Study Authors</td>
<td>Location</td>
<td>Sample Size</td>
<td>Sample Description</td>
<td>Data Collection Method</td>
<td>Data Analysis Method</td>
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<tr>
<td>Matthew et al., 2011</td>
<td>Canada</td>
<td>15 Men with a family history of PCa</td>
<td>Ethnic group not specified</td>
<td>Semi-structured interviews</td>
<td>Interpretative phenomenological analysis</td>
</tr>
<tr>
<td>Nanton &amp; Dale, 2011</td>
<td>UK</td>
<td>16 first generation Afro-Caribbean men diagnosed with PCa; living in the UK; 50-83 yrs.</td>
<td>Face to face interviews; thematic analysis</td>
<td>Urinary changes, 'stoppage of water' (p. 4)</td>
<td>Not serious</td>
</tr>
<tr>
<td>Ng et al., 2013</td>
<td>Barbados</td>
<td>33 African Barbadian men and women comprising PC survivors and men from the general public (Only findings of men included)</td>
<td>Face to face interviews</td>
<td>General prostate symptoms (p. 657)</td>
<td>Self-sufficiency</td>
</tr>
<tr>
<td>Study</td>
<td>Setting</td>
<td>Quality</td>
<td>Participants</td>
<td>Method</td>
<td>Symptoms and Phenomenology</td>
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<tr>
<td>O’ Brien et al., 2005</td>
<td>UK</td>
<td>FAIR</td>
<td>55 men; 15-72 yrs. Only accounts of men (4) diagnosed with PCa included (52-70 yrs.)</td>
<td>Focus groups</td>
<td>Aches and pains (p. 508) These were described as ‘normal’</td>
</tr>
<tr>
<td>Shaw et al., 2008</td>
<td>UK</td>
<td>GOOD</td>
<td>32 participants (15 women &amp; 17 men); over 40 yrs. Only findings of men included</td>
<td>Face to face interviews;</td>
<td>Urinary frequency 3 to 4 times a night (p. 1518) ‘Just the way you are’</td>
</tr>
<tr>
<td>Taghipour et al., 2010</td>
<td>Iran</td>
<td>GOOD</td>
<td>12 Iranian men diagnosed with PCa; 55-80 yrs.</td>
<td>Semi structured interviews; grounded theory methodology</td>
<td>Urinary changes: frequency, nocturia, dysuria (p. 6) ‘Five years ago, I got urinary problem... um (long pause with apologizing) such as going frequently to toilet, especially at night, and I had difficulty to start urination. Therefore, I thought that it’s a temporary difficulty and goes away soon. Nevertheless, it continued, and I thought that it’s an unusual problem’ ‘I tolerated my illness for 3 years. After that, I couldn’t, because I was not able to control my urine. The severity of my illness changed my mind and I tried to know more’</td>
</tr>
<tr>
<td>Hale et al., 2007</td>
<td>UK</td>
<td>GOOD</td>
<td>20 British men diagnosed with prostate disease; 51-75 years</td>
<td>Semi structured interviews; interpretive phenomenology</td>
<td>General prostate symptoms (p. 8) ‘We sort of shy off, no I don’t want to know, don’t want to find out, don’t want to know that if I’ve got it, it might go away’</td>
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</tbody>
</table>

Note: PCa = Prostate Cancer
<table>
<thead>
<tr>
<th>Topic</th>
<th>Description</th>
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</thead>
<tbody>
<tr>
<td>Urinary changes (p. 9)</td>
<td>I don’t consider myself ill. I can walk about and do things, I mean there’s people in there that aren’t very well at all bad hearts or whatever’</td>
</tr>
<tr>
<td>Impotence (p. 10)</td>
<td>‘I’m not the sort of person who would necessarily bother a GP or run to a GP very, you know, sort of straight away’</td>
</tr>
<tr>
<td>General prostate symptoms (p. 8)</td>
<td>‘She sat down and explained to me what the prostate was, where it was and the problems for men of my age and I felt a lot better because somebody sat down’</td>
</tr>
<tr>
<td>Urinary changes (p. 8)</td>
<td>‘…Treat it as a bit of a joke, because we do, the three of us, joke about it, but at the back of your mind but it isn’t’</td>
</tr>
<tr>
<td>Urinary urgency and leakage (p. 9)</td>
<td>‘I was working on a shopping mall a couple of weeks ago and, erm, on stands whatever, it’s just a case of once it overcomes you that’s the end of it and it was a case of, I couldn’t quite make it’</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>A minor problem</th>
<th>Would subside with time</th>
<th>Would bother his GP</th>
<th>Not serious or requiring medical attention</th>
<th>Going to GP is only for serious concerns</th>
<th>Self-monitoring help-seeking</th>
</tr>
</thead>
<tbody>
<tr>
<td>Men are supposed to be strong</td>
<td>Societal norms</td>
<td>Appear weak</td>
<td>Appear weak</td>
<td>Hegemonic masculinity</td>
<td>Not wanting to appear weak to HCP</td>
</tr>
<tr>
<td>Need attention</td>
<td>Worry and anxiety</td>
<td>Something wrong is happening</td>
<td>Worried that doctor would not take time to address concerns; felt Doctors were poor diagnosticians, had inadequate knowledge; Inept in physical examination.</td>
<td>Mistrust in doctors; Negative prior experience: lack of attention and empathy</td>
<td>Attended GP appointment; Not with attention</td>
</tr>
<tr>
<td>Serious</td>
<td>Social network</td>
<td>Symptoms would go away</td>
<td>Not needing medical attention</td>
<td>Hearing stories from others; fear and anxiety; belongingness</td>
<td>Needed reassurance from men with similar situations through socializing and sharing experiences of</td>
</tr>
<tr>
<td>Passing symptoms</td>
<td>Hegemonic masculinity</td>
<td>Protect image</td>
<td>Needed help to stop episodes of public exposure</td>
<td>Fear of being arrested for loitering</td>
<td>Carried on as no longer able to symptoms</td>
</tr>
<tr>
<td>QUANTITATIVE STUDIES</td>
<td>Self-reported bodily changes</td>
<td>Belief</td>
<td>Belief-base</td>
<td>Interpretation</td>
<td>Belief</td>
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<tr>
<td>Gülpinar et al., 2011</td>
<td></td>
<td>Erectile dysfunction</td>
<td></td>
<td>Medication could resolve; older people do not have sexual desire; it is a self-</td>
<td>Lack of knowledge</td>
</tr>
<tr>
<td>Turkey</td>
<td></td>
<td></td>
<td></td>
<td>limited/non-serious problem; Natural process of ageing</td>
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<tr>
<td>Quality = Good</td>
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<td></td>
<td>191 men who had never sought medical help for their erectile dysfunction; 20-80 years</td>
<td>Survey &amp; self-administered questionnaire; Men recruited in the waiting rooms of physicians in general practice, family practice, or general internal medicine</td>
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<tr>
<td>Metcalfe et al., 2008</td>
<td></td>
<td>General prostate problems</td>
<td></td>
<td>Concerned about symptoms</td>
<td>Fear</td>
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<tr>
<td>UK</td>
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<tr>
<td>Quality = Good</td>
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<td></td>
<td>193 Black men, 463 White men diagnosed with PCa</td>
<td>Population-based retrospective cohort study; questionnaire Multivariable regression methods</td>
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<tr>
<td>Shabsigh et al., 2004</td>
<td></td>
<td>Erectile dysfunction</td>
<td></td>
<td>Normal part of ageing</td>
<td>Lack of knowledge</td>
</tr>
<tr>
<td>UK, USA, Italy, Germany, France, Spain</td>
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<tr>
<td>Quality = Good</td>
<td>1938 men; 20-75 yrs.</td>
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<tr>
<td>Whitaker et al., 2014</td>
<td></td>
<td>Change in bladder habit</td>
<td></td>
<td>Physical (e.g. urinary tract infections)</td>
<td>Common health concern not to be bothered about</td>
</tr>
<tr>
<td>UK</td>
<td></td>
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<td></td>
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<tr>
<td>Quality = Good</td>
<td>1724 Men and women (White and other) over 50 years, not diagnosed with cancer</td>
<td>Questionnaire</td>
<td></td>
<td></td>
<td>Not cancer</td>
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<tr>
<td>Apostolidis et al., 2009</td>
<td></td>
<td>Urinary changes: nocturia, urgency, frequency, bladder emptying, weak urinary stream, stop-start urination.</td>
<td></td>
<td>Perceptions of bother (only) as</td>
<td>Lack of knowledge</td>
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</tbody>
</table>

...
<table>
<thead>
<tr>
<th>Greece</th>
<th>(Only men’s findings included for urology clinic)</th>
<th>no bother, little, some, a lot</th>
<th>symptoms warrant help-seeking</th>
<th>severity of urinary changes</th>
</tr>
</thead>
</table>

### MIXED METHODS STUDIES

<table>
<thead>
<tr>
<th>Emery et al., 2013</th>
<th>66 participants were recruited (24 breast, 20 colorectal, 14 prostate and 8 lung cancer patients). Only findings from PCa patients included</th>
<th>Self-reported bodily changes</th>
<th>Belief</th>
<th>Belief-base</th>
<th>Interpretation</th>
<th>Belief</th>
<th>Belief-base</th>
<th>Help-seeking</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Mixed-methods</strong></td>
<td>Haematuria</td>
<td>Frequency in urination (p. 298)</td>
<td>Danger</td>
<td>Knowledge</td>
<td>‘red flag’</td>
<td>Need to seek help</td>
<td>Knowledge</td>
<td>Sought help early</td>
</tr>
<tr>
<td></td>
<td>‘I used to wee, wee, wee all the time. Yeah. And I thought well I must be all right, you see and bloody hell, no it was doing me over for quite a while’.</td>
<td>Passing, not important</td>
<td>Peer-approval (Accounts of social contacts diagnosed with PCa)</td>
<td>Absence of pain meant nothing to be worried about</td>
<td>Can still manage, fear of diagnosis of cancer, embarrassment of procedures</td>
<td>Neither</td>
<td>Symptoms did not interfere with AODL; severity based</td>
<td>Did not seek help</td>
</tr>
<tr>
<td></td>
<td>‘Um, if I had of been an inside worker, I’d have probably been worried. But see when your outside worker you can just walk over behind the shed and have a squirt you know? Ah, an inside worker he’d have to be getting out of . . . going down the hall to have a . . . walking past everyone to have a pee all day. You know?’</td>
<td>Normal</td>
<td>‘I used to talk to people that had PCa . . . and that’s my friends, close friends, and I used to say well how do you know you’ve got it? They said, well Jesus, your belly swells up and you can’t pass your . . . your urine and . . . . . pain and that and that’s when they go to the doctor and I thought, no I had no problems’ (p. 298)</td>
<td>Nothing to be worried about</td>
<td>Not affecting AODL</td>
<td>Not severe enough to seek help</td>
<td>Delayed help-seeking</td>
<td></td>
</tr>
<tr>
<td>Study</td>
<td>Country/Region</td>
<td>Sample Size</td>
<td>Method</td>
<td>Symptoms</td>
<td>Main Reason Waiting</td>
<td>Knowledge Source</td>
<td>Impact of Disease</td>
<td>Experience Source</td>
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<tr>
<td>Ertel et al., 2016</td>
<td>Multi-global countries</td>
<td>1094</td>
<td>Survey</td>
<td>The need to urinate more frequently, urgency urinating, a slower or weaker urinary stream and getting up at night to urinate</td>
<td>The main reason given by patients for waiting was to see if the condition would go away on its own, Feeling embarrassed talking about it.</td>
<td>Lack of knowledge</td>
<td>Ageing</td>
<td>Viewed specialist doctors as more helpful than family doctors</td>
</tr>
<tr>
<td>Place et al., 2011</td>
<td>UK</td>
<td>458</td>
<td>Survey, telephone interview</td>
<td>Change in urination (p. 14) Pain when urinating Blood in urine or semen Erectile dysfunction Pain in back/hips/stomach/testicles Weight loss 'I didn’t give it too much attention really...it wasn’t desperately painful or anything like that, it was just, you know, annoying' 'I was reluctant, not because I thought it was PCa or anything, just because I didn’t think it was all that serious'</td>
<td>Normal body changes</td>
<td>Lack of knowledge</td>
<td>Painful, Troublesome Impact, Worrying Low, Serious Normal ageing Overdone things Related to other health problems Related to other prostate problems Infection Thought I might have PCa I couldn’t explain my symptoms (p. 21) I didn’t look for any other symptoms as I say, er...PCa was furthest from my mind, as I say, I just thought it was er...perhaps a problem with me getting older and...that, I didn’t you know, think it was anything major</td>
<td>Impact on everyday life</td>
</tr>
</tbody>
</table>

Quality = Good
<table>
<thead>
<tr>
<th>Study</th>
<th>Participants</th>
<th>Methods</th>
<th>Symptoms</th>
<th>Ageing</th>
<th>Lack of Knowledge</th>
<th>Ageing/Normality</th>
<th>Symptom Management</th>
<th>Symptom Impact</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sarma et al., 2008 USA</td>
<td>165 AA men; age 40-75 not diagnosed with PCa</td>
<td>Interviews; self-administered questionnaires</td>
<td>Urinary frequency, obstructive nocturia, irritative urinary symptoms, incomplete emptying and urgency.</td>
<td>Ageing was considered by researchers</td>
<td>Lack of knowledge</td>
<td>Ageing/normality</td>
<td>No need to see a doctor until symptoms become worse</td>
<td>Symptoms did not interfere with AODL; severity based</td>
</tr>
</tbody>
</table>
2.3 APPENDIX 3: SI- premises and assumptions and linkages with aims of study

Assumption 1. The external world is a symbolic representation, a “symbolic universe.” Both this and the interior worlds are created and recreated through interaction. In effect, there is no divide between external or interior world (Blumer, 1969).

Assumption 2. Meanings (symbols) are aspects of interaction and are related to others within systems of meanings (symbols). Interactions generate new meanings ... as well as alter and maintain old ones (Mead, 1934).

Assumption 3. Actions are embedded in interactions—past, present and imagined future. Thus, actions also carry meanings and are locatable within systems of meanings. Actions may generate further meanings, both with regard to further actions and the interactions in which they are embedded (Mead, 1934).

Assumption 4. Contingencies are likely to arise during a course of action. These can bring about change in its duration, pace, and even intent, which may alter the structure and process of interaction (Dewey, 1929).

Assumption 5. Actions are accompanied by temporality, for they constitute courses of action of varying duration. Various actors' interpretations of the temporal aspects of an action may differ according to the actors' respective perspectives; these interpretations may also change as the action proceeds (Mead, 1959).

Assumption 6. Courses of interaction arise out of shared perspectives, and when not shared, if action/interaction is to proceed, perspectives must be negotiated (Blumer, 1969).

Assumption 7. During early childhood and continuing all through life, humans develop selves that enter into virtually all their actions and in a variety of ways (Mead, 1959).

Assumption 8. Actions (overt and covert) may be preceded, accompanied, and/or succeeded by reflexive interactions (feeding back onto each other). These actions may be one's own or those of other actors. Especially important is that in many actions the future is included in the actions (Dewey, 1929).

Assumption 9. Interactions may be followed by reviews of actions, one's own and those of others, as well as projections of future ones. The reviews and evaluations made along the action/interaction course may affect a partial or even complete recasting of it (Dewey, 1929).

Assumption 10. Actions are not necessarily rational. Many are non-rational or, in common parlance, “irrational.” Yet rational actions can be mistakenly perceived as not so by other actors (Dewey, 1929).

Assumption 11. Action has emotional aspects: To conceive of emotion as distinguishable from action, as entities accompanying action, is to reify those aspects of action. For us, there is no dualism. One can't separate emotion from action; they are part of the same flow of events, one leading into the other (Dewey, 1929).

Assumption 12. Means-ends analytic schemes are usually not appropriate to understanding action and interaction. These common-sense and unexamined social science schemes are much too simple for interpreting human conduct (Strauss, 1993).

Assumption 13. The embeddedness in interaction of an action implies an intersection of actions. The intersection entails possible, or even probable, differences among the perspectives of actors (Strauss, 1993).

Assumption 14. The several or many participants in an interactional course necessitate the “alignment” (or articulation) of their respective actions (Blumer, 1969).

Assumption 15. A major set of conditions for actors' perspectives, and thus their interactions, is their memberships in social worlds and sub worlds. In contemporary societies, these memberships are often complex, overlapping, contrasting, conflicting, and not always apparent to other interactants (Strauss, 1993).

Assumption 16. A useful fundamental distinction between classes or interactions is between the routine and the problematic. Problematic interactions involve “thought,” or when more than one interactant is involved then also “discussion.” An important aspect of problematic action can also be “debate”—disagreement over issues or their resolution. That is, an arena has been formed that will affect the future course of action (Dewey, 1929; Strauss, 1993).
2.4 APPENDIX 4: Individual Interview Questions Guide (Men newly diagnosed with PCa).

**Before interview**

Greeting/Introductory question/statement: Good day. How are you today?
Ice breakers.
Thank you for taking time from your busy schedule to attend this interview.
Introductory questions: Can I offer you a cup of tea or coffee? Is there anything that I can do to make you more comfortable?

**Start of interview**

Introductory Question: “Can you tell me a little about yourself?”

**Body of interview**

“Can you share your experiences when you first noticed something was wrong?”
“Can you share your experiences from the moment you were feeling ill/displaying signs of illness to the point of going to the doctor?”

Probing questions:

“How did you find out about this?”
‘What did you do when you noticed something was wrong?’
‘What did you think?’ or “What thoughts were going through your mind/head when you noticed you were ill?”
Who did you talk to?’

“When did you find out about this?”
“What led you to come in to the hospital/clinic/private office?”

Questions about beliefs

“What did you believe was happening to you?”
“What do you believe caused it?” or “Why do you think you got PCa?” (Only when participant mentions ‘cancer’) “What are your beliefs about PCa?

“Who do you think can get this disease?”
“What traditional/religious beliefs, if any, do you hold/follow about PCa/cancer”?
“What does your partner/family/close friend believe about PCa/cancer?”
“What are your beliefs now?” (after diagnosis) or “Has your beliefs changed since you were diagnosed?”, “In what way has your beliefs changed?”

Questions about roles

What role did your partner/family/friends play in your health/illness?
“What role do you think your partner/family/friends have in this?”

“Looking back, is there anything that you would have done differently?”
“What would you have wished that you had done differently?”
What happened when you went to the doctor’s office? What help, or support, or information were you given?
What type of assistance/support/information would you have liked to be available?

**End of interview**

Concluding Questions: “Is there any other information you would like to share?”
Concluding statement: Thank you for attending this interview today. I do look forward to keeping in touch with you.
2.5 APPENDIX 5: Focus Group Interview Guide (Partners (women) of men newly diagnosed with PCa)

**Before interview**

Greeting/Introductory question/statement: Good day. How are you today? Ice breakers. Thank you for taking time from your busy schedule to attend this interview. Introductory questions: Can I offer you a cup of tea or coffee? Is there anything that I can do to make you more comfortable?

**Start of interview**

Introductory Question: “Can you tell me a little about yourself?”

**Body of interview**

“Can you share your experiences of your husband/spouse/significant other being ill?”

“How did you find out about this?”
“Did you go with him?”
“What did you do when you first found out about it?”
“Who did you talk to?”
“Did he share his experiences?”
“When did you find out about this?”
“What was your role in all of this?”

“Can you share your experiences from the moment he started feeling ill/displaying signs of illness to the point of going to the doctor?”

Can you tell me what happened when he went to see the doctor?

**Probing Questions**

‘Did you go with him?’
‘Did he share his experiences?’
‘What did you do when you first found out about it?’
‘What did you think?’
‘Who did you talk to?’
“When did you find out about this?”
‘What was your role in all of this?’
Questions about beliefs

“What did you believe was happening to him?”
“What do you believe caused it?” or “Why do you think he got PCa?” (Only when participant mentions ‘cancer’) “What are your beliefs about PCa?

“Who do you think can get this disease?”
“What traditional/religious beliefs, if any, do you and your partner hold/follow about PCa?”

“What does your family/relative believe about PCa?”
“What are your beliefs now?” (after partner’s diagnosis) or “Has your beliefs changed since your partner’s diagnosis?”, “In what way has your beliefs changed?

Questions about roles

“What role did you play in your partner’s health/illness?”
“What role do you think you have in this?”

“Looking back, is there anything that you would have done differently?”
“What would you have wished that you had done differently?”
“What happened when you went to the doctor’s office? What help, or support, or information were you given?
What type of assistance/support/information would you have liked to be available?

End of interview

Concluding Questions: “Is there any other information you would like to share?”
Concluding statement: Thank you for attending this interview today. I do look forward to keeping in touch with you.
2.6  APPENDIX 6: Demographic form for research participants

Code Name:

Age:

Marital Status:

Religion:

Ethnicity:

Educational Level:

Employment:

Other medical condition/health concerns:


2.7 APPENDIX 7: Research consent form

Men and their partners experience with prostate problems in Trinidad & Tobago.

Consent Form

I voluntarily agree to take part in the study on ‘Men and their partners’ experiences with prostate problems in Trinidad and Tobago’.

I have read and understood the Information Sheet provided. I have been given a full explanation by the researcher/s of the nature, purpose, location and likely duration of the study, and of what I will be expected to do. I have been given the opportunity to ask questions on all aspects of the study and have understood the advice and information given as a result.

I agree to comply with any instruction given to me during the study and to co-operate fully with the researchers.

I shall inform the researcher/s immediately if I suffer any deterioration of any kind in my health or well-being or experience any unexpected or unusual symptoms.

I understand that all my personal data will be anonymized and processed in the strictest confidence, and in accordance with the Data Protection Act (1998).

I understand that I am free to withdraw from the study at any time without needing to justify my decision.

I agree to the interview being audio-recorded for the study.

I agree to attend an interview with the researcher/s
I have been given adequate time to consider my participation and agree to comply with the instructions and restrictions of the study.

I confirm that I have read and understood the above and freely consent to participating in this study.

Name of volunteer (BLOCK CAPITALS) Signed  Date ........................................

Name of researcher/person taking consent (BLOCK CAPITALS) Signed & Dated

..................................................................................................................
Research Study: Men and their partners’ experiences of prostate problems in Trinidad and Tobago.

Introduction
My name is Michelle King-Okoye and I am a PhD student from the University of Surrey, United Kingdom. I am seeking your participation in this study.

What is the purpose of the study?
This study seeks to explore your experiences of prostate problems. The findings of the study can help develop healthcare in Trinidad and Tobago.

What happens if I agree to participate?
If you agree to participate in this study, you will be asked to sign a consent form, which shows that you have agreed to participate in the study. You will be contacted and asked to attend a face-to-face interview with one researcher, which can last for about an hour. This will be audio-recorded.

Why will the interview be audio-recorded?
The interview will be audio-recorded for the purpose of transcription (speech into written/printed document) and analysis. All audio recordings and transcriptions will be destroyed at the end of the study.

What are my rights?
As a participant, you have the right to ask questions and clarify any information before and during the study. You also have to right to withdraw at any time from the study.

What are the possible benefits of taking part?
If you decide to take part, you will contribute to the advancement of healthcare in T&T.

What are the possible disadvantages or risks of taking part?
There are no known risks or disadvantages of taking part in this study, as we will protect your confidentiality. If you are taking part in the face-to-face interview, we will send you a copy of the interview transcript (everything that you said during the interview typed-written) to verify what was said before we analyse it.

What happens when the research study stops?
The findings of this research may be published in academic papers and at academic conferences. The results will be communicated with health officials that are responsible for healthcare.
Do I have to take part in this research?
You are under no obligation to take part in this research. You can withdraw at any time without giving a reason even if you have signed the consent form. There will be no adverse consequences if you do so.

What if there is a problem?
Any complaint or concern about any aspect of the way you have been dealt with during the course of the study will be addressed; please contact Professor Sara Faithfull (s.faithfull@surrey.ac.uk) or Dr Anne Arber (a.arber@surrey.ac.uk).

What happens if I need counselling or more information about my health?
A counsellor will be available should you require counselling. Health care professionals can be contacted should you require further information about your health. The Trinidad and Tobago Cancer Society at 62 Rosalino Street, Woodbrook, (622-6827, Website: http://www.ttcancersociety.org/link) also provides information leaflets and brochures about your health.

Will my taking part in the study be kept confidential?
Yes. All information you give during the research will be anonymized, so that no one can identify you even when reading reports from the study.

Contact Details of the researchers
Michelle M. King-Okoye, PhD student, University of Surrey
Email: mking-okoye@surrey.ac.uk

Dr Anne Arber, Senior Lecturer in Cancer Care, University of Surrey
Email: a.arber@surrey.ac.uk

Professor Sara Faithfull, Professor of Nursing Practice, University of Surrey.
Email: s.faithfull@surrey.ac.uk

Who has reviewed the project?
The study has been reviewed and received a favourable opinion from the University of Surrey Ethics Committee and approved by the University of The West Indies Ethics Committee.

Thank you for taking the time to read this Information Sheet.
Research Study: Men and their partners’ experiences of prostate problems in Trinidad and Tobago.

Introduction
My name is Michelle King-Okoye and I am a PhD student from the University of Surrey, United Kingdom. I am seeking your participation in this study.

What is the purpose of the study?
This study seeks to explore your experiences of having a partner with prostate problems. The findings of the study can help develop healthcare in Trinidad and Tobago.

What happens if I agree to participate?
If you agree to participate in this study, you will be asked to sign a consent form, which shows that you have agreed to participate in the study. You will be contacted and asked to attend a group interview with other partners of men who have prostate problems, and two researchers which can last for about an hour. This will be audio-recorded.

Why will the interview be audio-recorded?
The interview will be audio-recorded for the purpose of transcription (speech into written/printed document) and analysis. All audio recordings and transcriptions will be destroyed at the end of the study.

What are my rights?
As a participant, you have the right to ask questions and clarify any information before and during the study. You also have to right to withdraw at any time from the study.

What are the possible benefits of taking part?
If you decide to take part, you will contribute to the advancement of healthcare in T&T.

What are the possible disadvantages or risks of taking part?
There are no known risks or disadvantages of taking part in this study, as we will protect your confidentiality. If you are taking part in the group interview, we will send you a summary of the interview transcript (everything that you said during the interview typed-written) to verify what was said before we analyse it.

What happens when the research study stops?
The findings of this research may be published in academic papers and at academic conferences. The results will be communicated with health officials that are responsible for healthcare.

Do I have to take part in this research?
You are under no obligation to take part in this research. You can withdraw at any time without giving a reason even if you have signed the consent form. There will be no adverse consequences if you do so.

What if there is a problem?
Any complaint or concern about any aspect of the way you have been dealt with during the course of the study will be addressed; please contact Professor Sara Faithfull (s.faithfull@surrey.ac.uk) or Dr Anne Arber (a.arber@surrey.ac.uk).
What happens if I need counselling or more information about my partner’s health?
A counsellor will be available should you require counselling. Health care professionals can be contacted should you require further information about your partner's health. The Trinidad and Tobago Cancer Society at 62 Rosalino Street, Woodbrook, (622- 6827, Website: http://www.ttcancersociety.org/link) also provides information leaflets and brochures about prostate problems.

Will my taking part in the study be kept confidential?
Yes. All information you give during the research will be anonymized, so that no one can identify you even when reading reports from the study.

Contact Details of the researchers

Michelle M. King-Okoye, PhD student, University of Surrey
Email: mking-okoye@surrey.ac.uk

Dr. Anne Arber, Senior Lecturer in Cancer Care, University of Surrey
Email: a.arber@surrey.ac.uk

Professor Sara Faithfull, Professor of Nursing Practice, University of Surrey.
Email: s.faithfull@surrey.ac.uk

Who has reviewed the project?
The study has been reviewed and received a favourable opinion from the University of Surrey Ethics Committee and approved by the University of The West Indies Ethics Committee.

Thank you for taking the time to read this Information Sheet.
## 2.10 APPENDIX 10: Risk assessment form

<table>
<thead>
<tr>
<th>NATURE OF RISK</th>
<th>PERSON AT RISK</th>
<th>MEASURES TAKEN TO MINIMISE RISK</th>
</tr>
</thead>
<tbody>
<tr>
<td>Risk of upset due to questions/issues.</td>
<td>Participants focusing on ill health and fear of complications and death.</td>
<td>Researchers are trained in research and advanced communication skills. A second researcher will be made available during interviews to provide immediate counselling and make appropriate referrals to key workers as needed. Researcher will ask questions in a sensitive and supportive manner Staff will assist with appropriate selection of interviewees.</td>
</tr>
<tr>
<td>Anonymity at all stages of data collection</td>
<td>&quot; Participants</td>
<td>&quot; All data and back-up copies will be anonymized and stored securely Code names will be used for participants</td>
</tr>
<tr>
<td>Maintenance of confidentiality</td>
<td>Researcher and [participants]</td>
<td>Informed Consent form Maintenance of rights to confidentiality Participants will be assured that information discussed will not be shared with any person that is not involved in the study.</td>
</tr>
</tbody>
</table>
August 11th, 2015

Ms. Michelle M. King-Okoye
Faculty of Health and Medical Sciences,
University of Surrey,
United Kingdom

Dear Ms. King-Okoye,

Approval to Conduct Research Project in the NCRHA

Reference is made to the subject at caption.

Please be informed that approval has been granted for research entitled – “Men and their partners’ experiences of prostate problems in Trinidad and Tobago.”

The commencement of this research indicates that you have understood and accepted the responsibility of maintaining the confidentiality of all data and information collected and processed.

The NCRHA wishes you every success in this undertaking, and looks forward to receiving a copy of your Project Report within two (2) weeks of completion.

Sincerely,

Chandradai Harry
Chief Executive Officer (Ag.)

x.c: Ms. Augiinee Singh - General Manager, Policy, Planning and Research, NCRHA
Public Health Observatory, NCRHA

Board Members: Dr. Rampersad Parasram (Chairperson), Ms. Sharla Alexander-Dolahile (Deputy Chairperson), Mr. Alimmudin Mohammed, Dr. Chandra Saroop, Mr. Kishore Maharaj, Ms. Joy Cruickshank, Mr. Ryan Ramcharan, Mr. Wezley Ali
2.12 APPENDIX 12: Letter of Ethical Approval: University of Surrey Ethics Committee (cont’d on p. 332)

Mrs King-Okoye
Health & Social Care
FHMS

21 August 2014

Dear Mrs King-Okoye:

**UEC ref:** EC/2014/91/FHMS

**Study Title:** Men and their partners’ experiences of prostate problems in Trinidad and Tobago

On behalf of the Ethics Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the submitted protocol and supporting documentation.

**Date of confirmation of ethical opinion:** 21 August 2014

The final list of documents reviewed by the Committee is as follows:

<table>
<thead>
<tr>
<th>Document</th>
<th>Version</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Covering letter from researcher in response to queries from the Committee, sent 03 July 14 and further queries sent 04 July 14. Protocol (tracked copy)</td>
<td>Sub. 04 Aug 2014</td>
<td>31 July 2014</td>
</tr>
<tr>
<td>Appendix 2: Focus Group Interview Guide (Partners (women) of men newly diagnosed with prostate cancer)</td>
<td>Sub. 04 Aug 2014</td>
<td></td>
</tr>
<tr>
<td>Appendix 3: Radar Assessment Tool</td>
<td>Sub. 04 Aug 2014</td>
<td></td>
</tr>
<tr>
<td>Appendix 4: Consent Form</td>
<td>Sub. 04 Aug 2014</td>
<td></td>
</tr>
<tr>
<td>Appendix 5: Participant Information Sheet – for men (tracked copy)</td>
<td>Sub. 04 Aug 2014</td>
<td></td>
</tr>
<tr>
<td>Appendix 6: Participant Information Sheet – for partners (tracked copy)</td>
<td>Sub. 04 Aug 2014</td>
<td></td>
</tr>
<tr>
<td>Appendix 7: Risk Assessment</td>
<td>Sub. 04 Aug 2014</td>
<td></td>
</tr>
<tr>
<td>Appendix 8: Draft letter of intent / permission to conduct study</td>
<td>Sub. 04 Aug 2014</td>
<td></td>
</tr>
<tr>
<td>Appendix 9: Courtesy note for participants</td>
<td>Sub. 04 Aug 2014</td>
<td></td>
</tr>
<tr>
<td>Appendix 10: Recruitment Poster</td>
<td>Sub. 04 Aug 2014</td>
<td></td>
</tr>
<tr>
<td>Appendix 11: Research Brochure for Health Personnel</td>
<td>Sub. 04 Aug 2014</td>
<td></td>
</tr>
<tr>
<td>Letter from Gregory Mieres confirming counselling support to participants, if needed</td>
<td>Sub. 04 Aug 2014</td>
<td></td>
</tr>
</tbody>
</table>
| Protocol Cover Sheet (tracked copy) | Sub.  
04 Aug 2014 |
|-----------------------------------|-------------|
| Summary of project                | Sub.  
04 Aug 2014 |

This opinion is given on the understanding that you will comply with the University's Ethical Principles & Procedures for Teaching and Research.

If the project includes distribution of a survey or questionnaire to members of the University community, researchers are asked to include a statement advising that the project has been reviewed by the University's Ethics Committee.

If you wish to make any amendments to your protocol please address your request to the Secretary of the Ethics Committee and attach any revised documentation.

The Committee will need to be notified of adverse reactions suffered by research participants, and if the study is terminated earlier than expected with reasons. Please be advised that the Ethics Committee is able to audit research to ensure that researchers are abiding by the University requirements and guidelines.

You are asked to note that a further submission to the Ethics Committee will be required in the event that the study is not completed within five years of the above date.

Please inform me when the research has been completed.

Yours sincerely

[Signature]

Dr Sophie Wehrens  
Research Integrity and Governance Officer, Research & Enterprise Support
APPENDIX 13: Letter of Ethical Approval: North West Regional Health Authority

February 15th, 2016

Ms. Michelle M. King-Okoye
The Faculty of Health and Medical Sciences
School of Health and Social Care
The University of the Surrey
Guildford
GU27XH

Dear Ms. King-Okoye

Re: Men and their Partners’ Experiences of Prostate Problems in Trinidad and Tobago

The North West Regional Health Authority wishes to convey approval to conduct the aforementioned research.

Please be advised that all findings are to be submitted to the office of the Chief Executive Officer, North West Regional Health Authority, #39 Dundonald Street, Port-of-Spain upon completion of research and before publication of same.

Thanking you in advance for your co-operation.

Respectfully

Mrs. Lauren K. Maharaj
General Manager,
Health Policy Research and Planning
NWRHA
Secretary, Ethics Committee
December 3, 2014

Mrs. Michelle King-Okoye, Dr. Anne Arber and Prof. Sara Faithfull
School of Advanced Nursing Education
Faculty of Medical Sciences

Dear Researchers

Men and their partners' experiences of prostate problems in Trinidad and Tobago (T&T)

Further to our letter of November 24, 2014 and your emailed amendments dated December 1, 2014, I am pleased to advise that your application for research on the topic captioned is approved on behalf of Ethics Committee.

Yours sincerely

Verrol Simmons (Dr.)
for Chairman, Ethics Committee
Faculty of Medical Science
August 17, 2015

23 Wortham Way
Steveange
Hertfordshire
SG2 9SH

Dear Mrs. Michelle Maxine King-Okoye

Re: Request to Conduct Research Study

Reference is made to the caption supra.

Reference is also made to your emailed correspondence dated May 28, 2015 with respect to permission to conduct research study in Tobago.

In light of this, approval is hereby conveyed for the undertaking of this initiative.

Upon completion, the Division will like to be avail with a copy of your findings so that we too can look at ways to improve the lives of the citizenry of Tobago and by extension Trinidad.

The Division do look forward to working with you, and best wishes in your endeavours.

Respectfully yours,

[Signature]

Division of Health and Social Services

c.c Dr. Wheeler, Obstetrics and Gynaecology
APPENDIX 16: Research poster for patients

Men and their partners’ experiences of prostate problems in Trinidad and Tobago (T&T)

Funded by The Scholarship and Advanced Training Division of T&T

Sponsor: University of Surrey, United Kingdom

We are conducting a research study to explore you and your partner’s experiences of prostate problems.

You may be eligible to participate if:

1. You have been recently diagnosed with prostate cancer within the last 6 months to a year (any age)
2. You are the partner of someone recently diagnosed with prostate cancer within the last 6 months to a year (18 years and above).
3. You are a resident of Trinidad and Tobago
4. You are able to speak and understand English well
5. You are mentally competent and physically able to participate

If you decide to participate in the study, you will be invited to attend an interview with a researcher, which may last for an hour. All information shared in this study will be kept confidential and a counselor will be available should you require counseling.

Health care professionals can be contacted should you require further information about your health.

The Trinidad and Tobago Cancer Society at 62 Rosalino Street, Woodbrook, (622-6827, Website: http://www.ttcancersociety.org/link) also provides information leaflets and brochures about your health.

If you are interested in participating in the study, please contact:
Ms. Michelle King-Okeye @ 473-6851
Email: m.king-okoye@surrey.ac.uk

You can also inform your doctor or nurse of your interest to participate.

Researchers

Michelle M. King-Okeye, Postgraduate (PhD) student, University of Surrey, UK
Dr. Anne Arber, Senior Lecturer in Cancer care and Palliative care, University of Surrey, UK
Professor Sara Faithfull, Professor of Nursing Practice, University of Surrey, UK
2.17 APPENDIX 17: Line-by-line coding (Interview 1)

Right now, I’m hypertension (co morbidity) so I have been going to the doctor for the hypertension (enrolled at public hospital). I was good then I was experiencing some pain (bodily change) that I wouldn’t wish for my worst enemy. Unbearable pain that could make a big man cry (hegemonic masculinity). At certain times I feel like I couldn’t walk, I couldn’t move. I was weak... (debilitating body changes) But basically what I used to experience was mainly back pain...just mainly back pain...(tolerable) until it was unbearable... (self-assessment & monitoring bodily changes). I worked at () but I haven’t been working because of the illness, it was difficult...you could (effects of illness) say...it took me about 3 months before (delayed symptom appraisal) I realize it’s really something I should go to the doctor (lack of awareness & need for help seeking) for...only when I couldn’t walk (trigger for help seeking). I used painkillers but that didn’t work (self-medication). With the sickness I was down...I was depressed about it (psychological effects of illness). There are some things I never really shared with anybody (non-disclosure) when the pain was too severe...it’s like I could give up on life now you know (giving up). That’s how far it had me. I said to myself (inner dialogue), I could bear it no more (symptom burden)’ (Adam, Tobago).
2.18  APPENDIX 18: Open coding showing properties and dimensions for the code ‘pain’.

<table>
<thead>
<tr>
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</tr>
</thead>
<tbody>
<tr>
<td>'I was experiencing some pain...mainly back pain'</td>
<td>Pain</td>
<td>Experienced this for 3 months before seeing a doctor</td>
<td>Back and leg</td>
<td>Pain was initially tolerable</td>
<td>Use of self-medication - pain analgesia</td>
<td>Pain progressively worsened, including weakness and inability to walk</td>
<td>Appraisal delay; help seeking delay</td>
</tr>
</tbody>
</table>
Adam is describing his pain as unbearable. The intensity of his pain ranges from 'just mainly' to 'unbearable' pain. The location of Adam's pain is in the back. The duration of his pain is approximately 3 months before he assessed this as needing medical attention. A relief strategy for his back pain was the use of OTC pain (self) medication. His trigger to seek help was when his pain became debilitating and OTC was ineffective towards pain management. He described this as inability to walk, move and weakness. Adam identified that his lack of awareness of the need to seek medical help delayed his appraisal of his back pain and subsequently his help seeking actions. The effects of pain were evident in Adam's inability to work and provide for his family. The demographic information shows that Adam is the main breadwinner and his partner is a housewife. Adam described how his pain level affected his masculine image, 'could make a big man cry'. The pain also made him feel depressed and influenced his non-disclosure of his experiences. He realized that he could not bear his back pain and experienced an inner dialogue in which he made a decision to seek help because of the symptom burden. Adam is hypertensive and attending clinic. However, he did not inform his doctor about this.

<table>
<thead>
<tr>
<th>Code note for pain</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adam is describing his pain as unbearable. The intensity of his pain ranges from 'just mainly' to 'unbearable' pain. The location of Adam’s pain is in the back. The duration of his pain is approximately 3 months before he assessed this as needing medical attention. A relief strategy for his back pain was the use of OTC pain (self) medication. His trigger to seek help was when his pain became debilitating and OTC was ineffective towards pain management. He described this as inability to walk, move and weakness. Adam identified that his lack of awareness of the need to seek medical help delayed his appraisal of his back pain and subsequently his help seeking actions. The effects of pain were evident in Adam’s inability to work and provide for his family. The demographic information shows that Adam is the main breadwinner and his partner is a housewife. Adam described how his pain level affected his masculine image, ‘could make a big man cry’. The pain also made him feel depressed and influenced his non-disclosure of his experiences. He realized that he could not bear his back pain and experienced an inner dialogue in which he made a decision to seek help because of the symptom burden. Adam is hypertensive and attending clinic. However, he did not inform his doctor about this.</td>
</tr>
</tbody>
</table>

To follow up with these sensitizing questions:
- Why did Adam self-manage his pains?
- Why didn’t Adam discuss his back pain with his GP?
- Why did Adam choose not to share with anyone about his feelings of depression and giving up?
## 2.20 APPENDIX 20: code note, theoretical note and operational note for code pain

<table>
<thead>
<tr>
<th>Adam's extract Aug 2015</th>
<th>Theoretical note</th>
<th>Operational note</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Code note for pain</strong></td>
<td>Adam did not discuss his back pain with his GP, and he experienced appraisal and help seeking delays due to his lack of knowledge and awareness of possible PCa symptoms.</td>
<td>To observe for other aspects of hegemonic masculinity</td>
</tr>
<tr>
<td>Adam is describing his pain as unbearable. The intensity of his pain ranges from ‘just mainly’ to ‘unbearable’ pain. The location of Adam’s pain is in the back. The duration of his pain is approximately 3 months before he assessed this as needing medical attention. A relief strategy for his back pain was the use of OTC pain (self) medication. His trigger to seek help was when his pain became debilitating and OTC was ineffective towards pain management. He described this as inability to walk, move and weakness. Adam identified that his lack of awareness of the need to seek medical help delayed his appraisal of his back pain and subsequently his help seeking actions. The effects of pain were evident in Adam’s inability to work and provide for his family. The demographic information shows that Adam is the main breadwinner and his partner is a housewife. Adam described how his pain level affected his masculine image, ‘could make a big man cry’. The pain also made him feel depressed and influenced his non-disclosure of his experiences. He realized that he could not bear his back pain and experienced an inner dialogue in which he made a decision to seek help because of the symptom burden. Adam is hypertensive and attending clinic. However, he did not inform his doctor about this.</td>
<td>Aspects of hegemonic masculinity are noted in the data: stoicism (bearing his pain until unbearable), self-reliance (self-managing his pains through OTC) and non-exposure of vulnerability (make a big man cry; I never shared with anybody (non-disclosure).)</td>
<td></td>
</tr>
<tr>
<td><strong>To follow up with these sensitizing questions</strong></td>
<td>-Is there a relationship between non-disclosure and hegemonic masculinity?</td>
<td></td>
</tr>
<tr>
<td>-Why did Adam self-manage his pains?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>-Why didn’t Adam discuss his back pain with his GP?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>-Why did Adam choose not to share with anyone about his feelings of depression and giving up?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
2.21 APPENDIX 21: Excerpt Research log

I attended one of my interviews at the Tobago Hospital. On arrival I was greeted quite warmly by oncology staff who facilitated the interviews. I set up the light refreshments that I had put together for the men. I ensured that these were balanced meals and adapted to the Tobago culture.

Before the interview
At this interview, I greeted Adam with a handshake and introduced myself as a researcher from the University of Surrey, UK, which I felt would maintain my role as a researcher separate to that of a cancer specialist nurse/lecturer. Adam immediately asked if I was from TT. His body language appeared unwelcome initially until I said that I was from Trinidad, but I was presently doing my PhD at the University of Surrey. He asked if I worked in Tobago and I said no. At that moment Adam appeared relaxed and he then stated that he felt comfortable to share with me. He said he preferred talking to someone like me, someone who was abroad but had an interest in TT. I asked him why was that? And he said that he didn’t trust the workers there and he had lots to share and wanted to be certain that I would take the information forward to The Ministry of Health without them being able to know it was him. He appeared a bit sad when he said this. I again assured Adam that all information given will be anonymized. He then indicated that his wife (not present) was interested in participating in the interview but that he was uncomfortable with this and I should not interview her even if she called me. He proceeded by saying that his decisions were related to the relationship culture in Tobago. I then asked if he preferred to be interviewed by a male researcher. However, he said he was quite comfortable with me and said we should get started.

Reflections
I considered my role as a researcher as identified on the PIS as a potential barrier to participants moving forward with interviews. I did not state that I was from TT and this may be important for the research participants to be aware of. However, prior to this I had a recruitment meeting with all interested participants, and I was now a bit concerned about this because I did not state this (that I was from Trinidad) at that meeting. Due to this observation, I need to state where I am from during the greeting phase at each interview. Another concern that Adam made me become aware of was that he felt better knowing that I was not working in Tobago. This made him comfortable to continue with the interview. I wondered why the issue of trust was raised. Adam was not happy with his wife taking part in the interview, which he highlighted as related to relationship culture. What is the relationship culture in Tobago?
needed to capture family roles and relationships in subsequent interviews and in relation to the literature. Due to Adam's wishes, I will not interview his wife. However, I need to explore the dynamics involved in couples’ and family relationships in context to routes to diagnosis of prostate cancer. If Adam did not wish for his wife to be involved in this research due to relationship culture, why did he choose to be interviewed by a female researcher? How does Adam’s view of women’s role differ from the couples’ relationship to the researcher relationship?

**During the interview**

Adam seemed sad whilst talking about his experiences. He spoke about his role as bread winner which made it quite difficult for him to balance his time at the doctor and keep working to provide for his family. This caused him to delay help seeking and tolerate his symptoms. His focus was his family and he identified his role as the head of the home and ensuring finances were constant to pay his bills and support his home. Adam did not report his symptoms to his doctor although they were painful until these became unbearable. Although Adam was sad, he maintained composure during the interview and stated that his back pains made a big man cry. I was conscious of my body language during the interview and maintained a warm and empathetic composure which allowed Adam to remain comfortable during the interview.

**Reflections**

Adam demonstrated hegemonic masculinity norms which made him stoic and hide his vulnerability. These norms hindered his help seeking and caused him to be silent about his pains even when he had access to his doctor. I need to locate how hegemonic masculinity norms are similar and different among men. What are the macro and micro factors surrounding Adam’s experiences apart from his role as bread winner? Do these factors impact on his experiences? Does Adam’s experiences reflect Tobago men? Or is this similar to men from Trinidad as well? Is there a relationship to hegemonic masculinity norms and not wanting his wife to participate in the interview? If there is, what areas are affected?
2.22 APPENDIX 22: Excerpt from transcript showing open coding (codes are in bold text)

Researcher: Thank you for coming in today for the interview. Is there anything that I can do to make you more comfortable?
Adam: I’m okay
Researcher: Alright, great (pause). Can you tell me a little about yourself?
Adam: In the sense of...?
Researcher: Like where you’re from... your family and where you work
Adam: Well...I’m married with two children, five grandchildren. I worked at (labourer) but for the while I haven’t been working because of the illness. Alright? (effects of the illness on work/breadwinner of family)
Researcher: Oh, I see (pause)
Adam: That’s basically it. With the sickness I was down. At first when I was down, I was depressed. But, after realizing I was sick, I say you know what, whatever God grants me. I say let me just enjoy it whilst it last. (beliefs and effects of the illness on self – depression, acceptance, fatalism)
Researcher: You said because of the illness you had to stop working. What was it about the illness that caused you to be down?
Adam: Well, what about the illness that I had to stop working for the time being?
Researcher: Yes
Adam: Well I was experiencing some pain that I wouldn’t wish for my worst enemy. Unbearable back pain that could make a big man cry. At certain times I feel like I couldn’t walk, I couldn’t move. I was weak. That’s what I mean by that. (symptoms experienced – back pain, weakness, limited mobility – affecting movements and ability to work; evidence of hegemonic masculinity norms)
Researcher: It must have been difficult for you (pause) Can you share your experiences when you first noticed something was wrong?
Adam: When I first noticed something was wrong ...paused...well first thing because of my ignorance, and I didn’t check my prostate before. That was far from my thoughts. (did not get tested for prostate cancer prior to experiencing symptoms)
Researcher: Okay...You said you didn’t check it
Adam: No... I never checked it
Researcher: Why was that?
Adam: As I said due to my ignorance (was unaware of prostate tests)
Researcher: Okay...I see.
Adam: Alright...but basically what I used to experience was mainly back pain, you know...just mainly
back pain... but I kept going to the doctor... eventually I went to the private doctor and I said give me a full screening... blood, everything... well I actually didn’t get through with it. Until eventually I ended up in the hospital (legitimized back pain experienced; delay in obtaining diagnosis)

Researcher: When you said you didn’t get through with it, what do you mean by that?

Adam: What I mean by it is this, at first going to the private doctor. At first it was like... Doc I explained my situation, I say that I want to be diagnosed with what I have... but my intention was that I wanted to be blood screened for everything. Well... But the most he did was to give me some pain killers and tell me come back next week. And when I went back the next week – same thing... more pain killers. Back and forth... And the pain just kept getting worse until it transferred to the legs. (symptom management obtained; pain killers ineffective; delayed diagnosis)

Researcher: You said that you had to be back and forth going to the doctor, how long did it take you?

Adam: It take about a month... and then the next experience was going to the hospital now. Back pain... the most they were giving me is pain killers. Pain killers and home... pain killers and home... pain killers and home until it was unbearable (disruptive symptoms) and then I went back to the hospital and a doctor named Dr F asked me if anybody told me about my PSA. I said no and she said its abnormal. And she said that the PSA should read 4 and that mine was reading 200 and something (further symptom management; delayed diagnosis; silence in reporting PSA results)

Researcher: So, at that point in time, what was going through your mind?

Adam: What was going through my mind?

Researcher: Yes, at that point in time?

Adam: At that point in time I was asking... what! I was coming here for the longest while and nobody was telling me anything (silence with staff) ... because they did the body works and they did some x-rays. So, within that two-month period I keep going to the hospital back and forth... back and forth... can’t walk... being frustrated. Its then one Friday I say you know what I went to a private doctor which is Dr M and he recommend that I come here, after giving him all the details (private healthcare)

Researcher: Here at the oncology unit?

Adam: (Nods head), but I also went to the hospital and I joined the clinic which they did a prostate test... okay...

Researcher: Okay... go on

Adam: Within that is home again and I can’t walk... same thing. So, when I went by Dr. Z and he say come here and I came here on that Friday and met with Dr C. After meeting with him – he was a blessing in disguise –

Researcher: What do you mean by that?
Adam: Because from the time I meet him he start going through the files and he diagnosed me he realized that I loaded with cancer (diagnosed at advanced stage)

Researcher: So, it was at that point you found out what you were diagnosed with cancer?

Adam: Well...yes.

Researcher: For the first time?

Adam: Yes...for the first time. Dr M had suggested that it was cancer, but he had no document of proof. Alright?

Researcher: Yes

Adam: Within a period of time I came here and then it took about...from the time I did the biopsy to when they tell me it is cancerous (diagnostic delay) ...I already had all the details

Researcher: So, from the time they took the biopsy to the time they told you what you were diagnosed with cancer how long was that period?

Adam: Approximately 3-4 months (diagnostic period)

Researcher: And during that time what was it like for you?

Adam: Well...how it is for me? I’ll be honest with you. I was smiling...if you understand what I mean

Researcher: Why were you smiling?

Adam: Because...Let’s say I was 100% dependent on the hospital to go ahead with my illness. It means they were the ones to tell me (silence in reporting diagnostic test results and diagnosis) what I have been diagnosed with and to treat me they would not be able to...because I would be done dead already...because the time span in between for these kind of illness, I find is too far if you understand what I mean (delays)

Researcher: Yes I understand

Adam: So from the day I had done the ahm...get the results from the biopsy till now they haven’t seen me (delays in reporting results; treatment delays)

Researcher: And what do you think caused that?

Adam: Administration...I say is administration...that is how I put it eh. I don’t want to lie right? I want to be honest

Researcher: Okay

Adam: Today is my next day to see the doctors at the clinic concerning my prostate and how it is cancerous. My last visit was on Friday 21st... sorry 24th of the 4th

Researcher: So that is April

Adam: And my next visit is on the 21st of the 8th, 2015

Researcher: Okay, so you’re looking from April to August (delays)

Adam: Right! They had recommended that I do an MRI...they haven’t seen the MRI as yet
Researcher: So, you haven’t done the MRI?

Adam: I did the MRI

Researcher: Okay, when did you have the MRI?

Adam: I did the MRI (pause) in the 4th month

Researcher: So are you saying since April you haven’t seen the results?

Adam: They haven’t seen the results...them here (meaning the oncology unit) have seen the results (diagnostic delays)

Researcher: So you’re saying that the hospital, they have not seen the MRI results but the oncology unit has?

Adam: Yes

Researcher: How do you know that?

Adam: Because I bring it for them to see

Researcher: Okay...I understand

Adam: So I went to the hospital and I told them, I said ‘hear what...I did an MRI and I did a bone scan. I did a CT scan. I say but the time factor in between to determine how to treat me within this period of time is important for these things. Is there any way possible I could get an earlier appointment so these doctors could decide what they are doing? And I was I put ah ....so basically, I am 100% dependent (dependency on staff) here (pointing towards the unit) (delays)

Researcher: In the oncology unit?

Adam: Yes, here at the oncology unit. I did a CT scan, I did that in February and as I told you yesterday the radiologist report is a no no in that

Researcher: What do you mean by a no no?

Adam: They haven’t got it! (diagnostic delays)

Researcher: So, they told you that they haven’t got the report?

Adam: Down to yesterday when I leave by you, I went into the department and I ask can you please get the radiologist report so that if I can get it, when I go at the clinic today, from since then till now I’ve been there every week asking for it. They told me yesterday when I go to the clinic, they will put it on the system...so they will be able to see what’s happening

Researcher: So, are you saying from since February until now August, you haven’t seen the CT scan report?

Adam: No not the CT scan, you will see the scan itself...but not the radiologist report. It’s a no no. Because on my file here I noticed on the outside of it is mark, “need the report of the CT scan”. (diagnostic delay)
Researcher: Oh I see
Adam: Although I went, I still took a peek, just like how I went for the bone scan and I went through the report and I see how I have deposit here, there (pointing at his legs), before the doctor told me (silence in reporting diagnosis to patient)
Researcher: So going back to what you said, you were getting severe back pain, and you went to the doctor then to the hospital.
Adam: Yes, first to the doctor then to the hospital
Researcher: At that point what did you believe was happening to you?
Adam: Hmm...really and truly I didn’t know because I don’t want to make...I ain’t no doctor so I didn’t want to make no diagnosis to myself to say I going that way or this way (unaware of symptoms of prostate cancer)
Researcher: Okay
Adam: I just wanted the relevant people to tell me what’s wrong...and that is what I wasn’t getting (reported silence among staff)
Researcher: Okay (pause) So what do you believe caused it?
Adam: When you say cause? Question
Researcher: What caused the prostate cancer?
Adam: I don’t know...as I may be repeating myself from the beginning maybe. I don’t know how prostate cancer does come about (unaware of prostate cancer symptoms) ...I never really asked too much questions about it. The only thing that I know is that I have it (silence experienced by Adam towards asking the doctor questions about his illness)
Researcher: Why was it... that you never asked too many questions about it?
Adam: Ignorance...life seems nice, everything good for me, so I’m ignoring the reality that exist...failing to go...(did not go to the doctor initially for prostate tests) because I goes to the doctor for everything else but excepting that
Researcher:Excepting which one...?
Adam: Prostate
Researcher: And why not that one?
Adam: Everything else excepting that...coincidentally. Because right now I’m hypertension, right. So, I have been going to the doctor for the hypertension, right? But you know...everything else...excepting that (sees his GP for hypertension)
### 2.23 APPENDIX 23: Summary Table of all participants: Key opinions of silence

<table>
<thead>
<tr>
<th>Participant</th>
<th>Key opinions of silence</th>
<th>Participant</th>
<th>Key opinions of silence</th>
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</thead>
<tbody>
<tr>
<td>Adam</td>
<td>Nobody told me about my PSA test...that it was high. I didn’t tell my doctor about my back pains. Who am I? I’m a normal man on the streets</td>
<td>Lin</td>
<td>I feel it’s because the clinics can be quite busy its why doctors don’t really talk. They probably don’t have the time</td>
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<tr>
<td>Alex</td>
<td>They never told me the cancer could still come back...after they removed my testicles. But we don’t really talk about these things. But they know about certain bush and whatnot that could help. I would say that I can be a bit secretive about it...maybe that’s why I didn’t talk about it with you at first.</td>
<td>Jewel</td>
<td>I did my research and I noticed certain things that the doctor didn’t tell us like what stage the cancer is at. So, I asked him about that.</td>
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<td>Stan</td>
<td>Nobody really sit down and talk to you like to say to counsel you. I never asked them because I didn’t think I could ask</td>
<td>Tamara</td>
<td>Firstly, Greg doesn’t like me to ask questions. He wants to know something, but he prefers to say nothing. I asked around to find out and I heard that they also test biopsy private, so I tell him lets go privately and get a second opinion.</td>
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<td>Pete</td>
<td>Doctors don’t really talk to patients and I could understand that because they’re busy people. I never felt I need to ask doctors anything. They studied medicine and I think they should be the ones to tell me. I shouldn’t ask</td>
<td>Rio</td>
<td>&quot;Times are slowly changing but I could remember when I was a teenager. I wouldn’t tell any of my classmates or my teacher if I was getting period pains. I would just cry in a corner...it was private for me. I don’t really like talking about my husband’s problems. This is the first time I’m here sharing with other women.</td>
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<td>Tim</td>
<td>Doctors don’t tell you everything unless you question them. And they don’t like you to question them. I usually question people because of my job</td>
<td>Wilma</td>
<td>My husband coming here for about 2 years and we never got someone to sit and talk to us yet. It’s always a rush</td>
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<tr>
<td>Chris</td>
<td>I was waiting for them to tell me about how I was feeling. They are the experts</td>
<td>Petra</td>
<td>&quot;He didn’t tell me anything. I found it strange when Frank said he had to travel to the UK. But I didn’t realize that he had planned on going there to hide his pains from me. It affected our relationship because I was wondering what’s going on. He just left work and after a few months or so he came back and that was when he told me the truth, that he was battling with pain and other problems.</td>
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<td></td>
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<td></td>
<td>I wanted to go privately but I couldn’t afford it because the public hospital is the worst. To even get a doctor to see you or touch you you are lucky</td>
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<td>Luke</td>
<td>I had to keep asking them about my illness because they weren’t saying anything about my test results. But they didn’t tell me that I had to take the antibiotics before getting the procedure.</td>
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<td>Natasha</td>
<td>We still don’t know what’s happening. It’s about a few years. We came from the health centre and the doctors didn’t say anything about it.</td>
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<td>Nat</td>
<td>I made an appointment but by the time they see me, I was tired. Nobody touch me or anything. The doctor write up the prescription and I was out and still in pain.</td>
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<td>Mark</td>
<td>I believe in doctor’s ability to heal. I feel I shouldn’t question them.</td>
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<td>Cheryl</td>
<td>The nurses here don’t like you to bother them. I spoke to a few of them and I didn’t like how they attended to me. I think it’s the attitude which comes when they’re busy. Nobody likes talking...everybody’s quiet just doing their job and when you ask a question, they don’t like it.</td>
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<td>Adrian</td>
<td>I know it have something to do with the prostate...like cancer or something but I don’t know how bad it is. The doctors didn’t say.</td>
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<td>Clement</td>
<td>They only concentrate on writing notes no talking and I feel rushed. At that time my wife and I were not on speaking terms. She realized something was wrong because I just wasn’t there...I was at home, but I wasn’t really talking or anything. Normally we do everything together, so she was concerned that something was wrong. I had to be alone for a while.</td>
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<td>Paula</td>
<td>The staff doesn’t really tell you about what’s going on. Like the tests results takes a long time to get and they wouldn’t say anything unless you ask them.</td>
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<tr>
<td>Eric</td>
<td>It have a set of young doctors here. You hardly ever see older ones. They pass the catheter and I am waiting for my treatment.</td>
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<td>Floyd</td>
<td>I never ask them anything because firstly they don’t look at you.</td>
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<td>Tia</td>
<td>I question the doctors about my husband because he would never ask them anything. They don’t like it, but I ask so I could know what’s going on.</td>
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<td>Tom</td>
<td>I prefer the older doctors. Since I’ve been here it’s only once I saw a senior doctors. I know the young people need to be trained but sometimes I wish I could get the seniors to attend to me to tell me what’s happening with me.</td>
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<td>Baxter</td>
<td>The doctors and nurses here don’t explain anything to you, like what’s happening with you, how the test results reading. That’s why I don’t believe I have cancer.</td>
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<tr>
<td>Naomi</td>
<td>I ask the doctors and the nurses about my husband so I can know more about the prostate and the cancer. I also did reading on the internet.</td>
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<td>Tyrell</td>
<td>I don’t believe in asking the doctors or nurses anything. I believe they have their work cut out for them and that is their duty.</td>
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<tr>
<td>Participant</td>
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<tr>
<td>Kinsley</td>
<td>Firstly, nurses and doctors are trained to do this but there are plenty sick people, that's why they have to keep it short most times. Thank God for a girlfriend who was working as a cleaner in the clinic. She told me that a lot of men dying from this thing and she said you better get checked. She said that some men have it and it wouldn't show any signs. And that was what got me here in the first place. I didn't know that they could test for these things.</td>
<td>Charity</td>
<td>The nurses here have attitude. When you ask them something, they will tell you that is not for them that is for the doctors to answer.</td>
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<tr>
<td>Dan</td>
<td>Some of these doctors don't even sit down to discuss anything properly. They're always in a hurry.</td>
<td>Patsy</td>
<td>Well we are here, and he is in the hands of these doctors. I am praying that God speak to these doctors to help my husband and give them knowledge and direction because they're not saying anything to us.</td>
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<tr>
<td>Cameron</td>
<td>I understand that doctors are busy, so I try not to add to it. That's why I go privately. Every time the doctor does the PSA, I always ask them how its reading so I would have an idea if its high or low; or how the prostate feeling.</td>
<td>Jane</td>
<td>This was after the doctor told him that it was cancerous. He didn't explain what will be the next steps and just left him hanging like that. So, I contacted a doctor from abroad about robotic surgery.</td>
</tr>
<tr>
<td>Kodi</td>
<td>I still don't know what I'm diagnosed with because the doctors never really said anything to me. I know that I am sick, and I am here for them to do something about it. Still waiting on them to say well what is what.</td>
<td>Theresa</td>
<td>This is the 3rd time they cancelled him and didn't say anything until we come in</td>
</tr>
<tr>
<td>Jason</td>
<td>The doctor said nobody told you that you have prostate cancer. I jumped when I heard that because he said it had been in my files for months now, but nobody told me that I had cancer. I never asked the doctor if I could have sex after surgery as I feel a way to ask him that especially since they hardly taking</td>
<td>Sandy</td>
<td>It's so busy and you will spend a day in the hospital, and nobody will attend to you. Since we coming here nobody never touch my husband or look at his belly or his back. He's been getting problems with his back and the urine.</td>
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</table>


| Cain | I felt these were connected somehow with my sugar or something like that, but I didn’t know how to make sense of it, so I didn’t tell my doctor about it (erectile dysfunction) | Seth | Every time I go to see a doctor, I see a different doctor and it’s the same thing...no talking, two minutes and you’re out | Leo | I am not in the medical field to know what it is, so I didn’t ask. I would have asked him why wait for so long? But you know they are doctors, why question them? |
| Put | I really never ask them questions as it is their duty to tell me | Damien | I never heard anything about the prostate and how you could get it tested. This is not even advertised on the tv. Why the doctors don’t talk about prostate cancer. They not doing enough | Willo | Look how busy the place is. Every time I come if a doctor see me, I am lucky. Sometimes they will just cancel your appointment without even telling you and I come from far |
| Harry | You see doctors are like God so when you see them, they expect you to keep quiet as a sign of respect. Not everything they tell you, you should believe. | Matt | I never really told anyone about my erectile problem. This is the first time I am talking about it but it ent really bothering me or anything like that. I didn’t tell my wife but eventually she find out | Randy | There is a book to put in your appointment when you come in. Sometimes you come early but it crowded. The doctor will just come out and tell you he can’t see you. Just like that. Why they didn’t tell me this before wasting my time to come in |
| Glen | I never really ask questions as I believe the doctors should tell me what’s happening | Rick | I prefer the pharmacy than going in to the hospital because most times you don’t get a doctor to see you. They don’t ever talk to you so never bothered going in | Clarence | The urine was dripping but I thought it was the sugar, so I didn’t tell the doctor about it |
| Wes | Nobody told me what to expect for the tests. I didn’t know it would be so painful. | Roland | ‘My wife had a stroke and she is still recovering. She is eighty percent there, so I don’t want to add to her burdens. I want her to get better. So, if I’m not feeling well, I wouldn’t let her know. She’s already low and I don’t want her to start worrying about me | Colin | Every time I have to call an ambulance it takes a few hours for them to get here. By the time you get to the hospital nobody says anything and then you’re out and still don’t know what’s wrong with you |
| Paul | ‘I wanted to know what he meant by a spot on my prostate, but I never asked. And he never asked me if I had questions as well. That pushed me to go privately. Money talks. | Ronny | The doctor did tell me to come back if I have a problem, but I felt I could manage the urine and the back pain | Xavier | I was scared and I wasn’t sure because they didn’t really tell me what it would be like for the tests and my treatment. But my niece is a doctor and my wife has a cousin who is a doctor. They helped me to get things faster...the biopsy at the hospital. |
| Greg | Well, my doctor told me that my biopsy was suspicious, but he didn’t explain further what it meant, and he still hasn’t said anything about my PSA. I would wait on him to tell me. | | | | | N.B. (negative case representations are in bold) |
Silence among Afro-Caribbean men diagnosed with prostate cancer in Trinidad and Tobago: A grounded theory study

By

Michelle Maxine King-Okoye

END OF THESIS