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The development of an online intervention to support men during the cancer early detection period: Men in Limbo

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Abstract

Objective: With cancer incidence rates rising, there is a growing need to detect cancers early, before they metastasise to other organs, as late diagnosis is associated with lower survival, increased morbidity, poorer outcomes, and increased costs. Detecting cancer early has been a goal of cancer research for many years and although recognised as a time of uncertainty and distress, there is limited research that identifies the support needs of men during the period. Therefore, exploratory work is needed to identify and understand more comprehensively the experiences and support needs of men during the period to inform the development of appropriate self-management support interventions.

Design: The research comprises four inter-related studies: a mixed methods systematic review, a qualitative interview-based study, a prioritisation consensus study, and an arts-based peer participatory study.

Methods: For the systematic review, a comprehensive literature search was undertaken with five databases, and included studies that employed qualitative or quantitative methodology. The study presented empirical findings which focused on the effectiveness of interventions for men during the early detection period of cancer. The second study, a qualitative retrospective study, conducted in-depth semi-structured interviews with 25 men who had experienced the early detection period. Data were analysed using inductive data-driven thematic analysis. The findings from the interviews were taken to the next qualitative study which was conducted with 8 men, and used a nominal group technique methodology to prioritise the identified needs. Data were analysed quantitatively using a ranking and scoring system, and qualitatively using thematic analysis. The penultimate study, with an arts-based peer participatory (digital story) approach, was conducted with four men who had lived experience of the early detection period. Data were analysed using thematic analysis. The last study used the findings from the previous studies to build the ‘Men in Limbo’ intervention using two evidenced-based frameworks to clearly outline the content and process.

Findings: The first study demonstrated limited evidence for interventions supporting the use of information, education and professional input to improve outcomes for men during the early detection stage of cancer. The second study established a range of identified needs, including the value of social connectivity and the importance of information to build knowledge, support independence and provide a sense of control. The following study demonstrated the highest prioritised needs of men, including a priority for: planning and preparation; effective communications, and; social support. The penultimate study demonstrated the acceptability and benefit of an arts-based participatory approach to engage men in sharing their experiences of the early detection period of cancer. The cumulative findings from the studies were used in the development of an online self-management intervention presented as ‘Men in Limbo’.

Conclusion: This thesis, using multi-method approaches, provides a range of novel findings in relation to the lived experiences of men during the early detection of cancer. It provides the first mixed methods systematic review conducted that identifies the effectiveness of interventions to improve outcomes for men during the early detection period of cancer. The thesis applies thematic analysis to explore, define and distinguish distinct dimensions of need from the lived experience perspective and provides a hierarchy of greatest need via a transparent consensus process. This thesis demonstrates the acceptability of the digital story process as an arts-based peer participatory approach to engage men and transfer knowledge between peers, sharing experiences of the early detection period of cancer for benefit. It demonstrates the case, and opportunity, for the development of support interventions to address the needs identified and presents the development of an online self-management intervention ‘Men in Limbo’.

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Abbreviations

BAME – Black, Asian and Minority Ethnic

BCSP - Bowel Cancer Screening Programme

CASP - Critical Appraisal Skills Programme

CBT - Cognitive Behavioural Therapy

CCSKS-m - Modified Colorectal Cancer Screening Knowledge Survey

CNS – Clinical Nurse Specialist

COM-B model - Capability, Opportunity, Motivation and Behaviour model

CRC - Colorectal Cancer

CRD - Centre for Reviews and Dissemination

DRE - Digital Rectal Examination

DST - Digital Story Telling

FACT-C - Functional Assessment of Cancer Therapy Colorectal

GBT - Gay, Bisexual and Transgender

gFOBt - guaiac Faecal Occult Blood test

GP - General Practitioner

HCPs - Health Care Professionals

IES - Impact of Event Scale

MeSH – Medical Subject Headings

MMAT - Mixed Methods Appraisal tool

MRC - Medical Research Council

NCSI - National Cancer Survivorship Initiative

NGT – Nominal Group Technique

NICE – National Institute for Health and Care Excellence

NHS – National Health Service

PAR - Participatory Action Research

PHE – Public Health England

PHQ-8 - Patient Health Questionnaire

PSA - Prostate Specific Antigen

PRISMA – Preferred Reporting Items for Systematic Reviews and Meta-analyses

PRISMS - Practical Systematic Review of Self-Management Support for long-term conditions

PTG - Post-Traumatic Growth

SMS – Self-Management Support

TIDieR -Template for Intervention Description and Replication

TRUS-B -Trans-Rectal Ultrasound Scan and needle Biopsy

UK – United Kingdom

USA – United States of America

WHO - World Health Organisation

Chapter 1 – Introduction, background and context

This thesis, consisting of a systematic mixed methods review and three qualitative empirical studies, outlines the development of a self-management online intervention to support men during the cancer early detection period. The studies explore the needs of men during the cancer early detection period, their experiences of interacting with self-management support interventions, and their priorities for provision of support interventions to meet their needs. It is imperative to explore the development of support interventions to address the needs of men during the cancer early detection period, given that it has been identified as a period of stress and anxiety (Halbert et al., 2010) as men wait with uncertainty as to whether they have cancer. The current gap in provision of support for men during the cancer early detection period offers an opportunity to potentially impact future screening or detection adherence (Paskett, Harrop, & Wells, 2011) and choices after diagnosis (Denberg et al., 2006; Dillard et al., 2017; Drageset & Lindstrøm, 2005; Widerman, 2004).

This chapter gives an introduction, background and overview by exploring the evidence base and reviewing the wider literature, in order to set out the context in preparation for the following chapters. The evidence presented lays the foundations and contributes to the case for an online support intervention for men, by identifying important key factors to improve their psychosocial support and wellbeing during the cancer early detection period. The chapter concludes with the research questions to be considered in this thesis.

Key terms

It is important to define several specific terms used in this thesis to aid clarification and understanding. Early detection of cancer denotes that a tumour is in situ or localized and has not spread to other parts of the body (Etzioni et al., 2003). The 'early detection' of cancer refers to two important components: the early diagnosis of cancer, via diagnostic tests, for those who have symptoms, and; cancer screening programmes for the asymptomatic population. Early diagnosis relies on individuals recognising the potential warning signs or symptoms of cancer (such as lumps or abnormal bleeding), and seeking medical help and undergoing diagnostic testing. This includes procedures such as biopsies or ultrasound of lumps or organs affected to determine if cancer is present. The second component to detecting cancer early generally relies on screening the asymptomatic public to identify individuals who have a higher risk of developing cancer than others. Therefore, for the purposes of this thesis, the early detection of cancer period is defined as the time point from either attending asymptomatic screening or a diagnostic test, up to when the test results are confirmed, and will be referred to as the 'cancer early detection period'.

The term ‘self-management’ is referred to as the ability to ‘monitor one’s condition and to affect the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life’ (Barlow et al., 2002, p. 178). Self-management is not solely the responsibility of the individual, it is a collaborative approach, with support from the health care system. It is important to differentiate between self-management and self-management support. Activities that provide support to individuals with the self-management of their condition are referred to as self-management support (SMS). SMS consists of a range of multi-dimensional interventions, that include access to advice, and information or provision of resources (Kielmann et al., 2010). There are multiple components to SMS interventions, a taxonomy of self-management support interventions is used as a framework to describe and aid classification of components (Pearce et al., 2015) within the thesis.

‘Psychosocial’ is commonly used within health psychology and social science literature. However, there is not a universally agreed definition of it. The *Oxford English Dictionary* offers the definition of ‘psychosocial’ as ‘pertaining to the influence of social factors on an individual’s mind or behaviour, and to the interrelation of behavioural and social factors’ (Oxford English Dictionary, 2007). The consensus typically incorporates both the psychological factors (such as anxiety) and social factors (such as social support from a spouse, family or peer). For the purposes of this thesis, the term ‘psychosocial’ will refer to the psychological health and social support of men during the cancer early detection period. Although psychological issues cover a broad spectrum of issues, specific focus will be given to the common constructs of anxiety and distress, given the prevalence of them during the cancer early detection period (Awsare et al., 2008; Dale et al., 2005; Ellman et al., 1989; Gustafsson et al., 1995; Lu et al., 2016; Medd et al., 2005).

The concept of psychological distress is broadly defined as ‘the maladaptive psychological functioning in the face of stressful life events’ (Abeloff et al., 2000, p. 556) and the term is often discussed in the nursing, medical, psychological, and social science literature (Bruch, Rivet, & Laurenti, 2000; Lazarus, 1999; Massé, 2000). It is commonly defined in medical literature as a state of emotional suffering, characterized by symptoms of depression (Drapeau, Marchand, & Beaulieu-Prevost, 2012), sadness, and distraction (Ridner, 2004). The term is specifically used to describe emotions that affect functioning and interfere with daily living, and can result in distorted views of the self and circumstances (Ridner, 2004).

The use of the term ‘masculinities’ is widely accepted within the sociological field in recognition of the range of the different groups of men and the diversity associated with them (O’Brien, Hunt, & Hart, 2005). It is recognised that men display their masculinity, in terms of their health, in a multitude of ways (Connell & Messerschmidt, 2005; Courtenay, 2011), and evidence suggests that some men are more likely to conform to the historic masculine stereotype of men's perception of the need to be strong, stoic and macho (Wilkins, 2013).

Background

Cancer is one of the major causes of morbidity and mortality worldwide, with 14 million new cases and over 8 million deaths recorded in 2012 (World Health Organisation [WHO], 2012). Cancer has a significant impact on individuals, families, wider society and the healthcare system. Prevention strategies, such as detecting it early, can reduce the burden of cancer. The spread of cancer from a primary tumour, referred to as metastatic cancer, is the main cause of death in around 90% of people living with cancer (Chaffer & Weinberg, 2011; Gupta & Massague, 2006; Seyfried & Huysentruyt, 2013). Therefore, it is widely accepted that the earlier cancer is detected the higher chance of survival (Etzioni et al., 2003; McPhail et al., 2015; Wolf et al., 2010) and less invasive treatment and metastatic disease (Uttley et al., 2016).

Early detection rates in the United Kingdom are lower than many other Western countries (Elliss-Brookes et al., 2012). For the general population, opportunities for early detection are limited to either cancer screening programmes or incidental radiological findings. In 2006, the English National Health Service (NHS) introduced one of the three cancer screening programmes, the Bowel Cancer Screening Programme (BCSP) to improve the outcomes and mortality of colorectal cancer (CRC) by its earlier detection and prevention (Koo et al., 2017). The incidence of CRC in the UK has risen by 5% in the last 10 years. It is the third most common cancer diagnosis, and the second most common cancer death, with a 5-year survival of 59% (Cancer Research UK, 2016). Recent figures indicate uptake of bowel cancer screening to be lower for men than women (53% for men and 58% for women; Public Health England, 2014). The screening programme invites eligible patients, those aged between 60-74 years, to complete a home-based guaiac Faecal Occult Blood test (gFOBt) which identifies traces of blood in the participants' faeces. Within approximately 2% of the samples taken, blood is present, and followed up with a diagnostic test (usually a colonoscopy) (Logan et al., 2012). The CRC screening approach has been associated with a 15% reduction in CRC mortality (Hardcastle et al., 1996; Koo et al., 2017).

All of the three screening programmes in England - cervical, breast and colorectal (bowel) - do not recall older age groups (generally around 74 years and above), as research indicates it is less effective and leads to over diagnosis, causing more harm (Bulliard & Chiolero, 2015).

However, cancer in older adults is less likely to be detected early, and emergency presentation diagnoses increase proportionately with age (Public Health England, 2015). Research is being conducted to explore the introduction of new generic blood tests which should improve early detection, while increasing the population of patients identified ‘at risk’ or living with early pre-symptomatic cancer (Uttley et al., 2016).

Figure 1 – Distinguishing screening from early diagnosis according to symptom onset

(World Health Organisation, 2017)

It is imperative to detect cancer early, as late diagnosis is associated with lower survival, increased morbidity, poorer outcomes (Department of Health, 2011a; National Cancer Survivorship Initiative, 2013), and increased costs (as the later the stage it is detected, the higher the costs of treatment) (Department of Health, 2011b; Incisive Health, 2014). To reduce the length of the diagnostic interval, in 2000 the UK introduced the 2-week wait referral (2WW) (Department of Health, 2000). More recently the National Cancer Transformation Board outlined a range of steps designed to support early detection, speed up diagnosis and improve the experience of patients in the published ‘Achieving World Class Cancer Outcomes: Taking the strategy forward’ (NHS England, 2016a, 2016b). The strategy outlined the introduction of a new 28-day faster diagnosis standard, designed to ensure that patients find out within 28 days whether, or not, they have cancer. Certain areas, such as the rapid diagnosis and assessment centres are currently putting the standard into place however full uptake of the standard is expected by 2020 (NHS England, 2016a, 2016b). The focus of the standard is on reducing variation for patients and providing a consistent timed pathway to enable patients to have their diagnosis communicated to them in the shortest time possible (as illustrated in Figure 2).

Figure 2 – Cancer diagnostic pathway

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(NHS Improvement, 2018)

However, there is growing evidence to suggest that the period between testing and results can be more distressing than receiving the diagnosis of cancer (Dale et al., 2005; Fantini-Hauwel et al., 2011; Liao et al., 2008). The waiting time could be described as a 'liminal state', or a time spent 'in limbo': there is not a confirmation of illness and yet the threat imposed (of a possible diagnosis) has the ability to affect the individual, their identity and other aspects of their life. One of the reasons that uncertainty fuels anxiety and distress during the cancer early detection period may be due to the ambiguity of what Gillespie (2009) suggests is the experience of 'declassification' without 'reclassification'. Individuals, although asymptomatic, may waiver as they contemplate the threat of illness and anticipation of disease, because they are not ill, but no longer deemed healthy. This can lead to feelings of not being in control as time is spent considering the outcome, managing uncertainty (Greene et al., 2012), and navigating difficult communications (Bisson et al., 2002; Brown, Oetzel, & Henderson, 2016; George & Fleming, 2004).

A number of studies have found a positive correlation between the experiences in cancer early detection period and the effect on diagnosis and post-diagnosis periods (Drageset & Lindstrøm, 2005; Widerman, 2004; Zhu et al., 2018). This suggests that it may be possible to identify individuals earlier who may be more predisposed to experiencing heightened distress further along the cancer trajectory, at diagnosis and beyond. It is still largely unknown what the long-term implications of heightened levels of distress might be, and it could be argued that this under-researched area holds opportunities to enhance further screening adherence, patient experience, clinical outcomes and health economics (De Silva, 2011; Knapp, McDaid, & Parsonage, 2011; Paskett, Harrop, & Wells, 2011). Identifying the holistic needs of men before diagnosis has received little attention and there is a need for further investigation regarding the extent to which the level of distress experienced affects the individual and those around them. It is imperative that individuals feel supported during this initial stage, as it may have an impact on future screening or detection adherence (Paskett, Harrop, & Wells, 2011). Some individuals with a higher risk of breast cancer have been found to experience increased cancer anxiety during the cancer early detection period (Cameron & Reeve, 2006; Dillard et al., 2017). Several studies suggest that significant levels of anxiety and distress can inhibit careful information processing (Dillard et al., 2013). A study with women deciding whether to have genetic testing for breast cancer discovered that as women's anxiety increased, their comprehension decreased (Lerman et al., 1995). In a similar study women's interest in testing increased as their knowledge, and the perceived benefits of testing, increased for participants with low anxiety (Cameron & Reeve, 2006). However, in the same study women with high anxiety, were found to be interested in testing regardless of their knowledge, or their perceived benefits, of the treatment (Cameron & Reeve, 2006). Similarly, an increased interest in risk-reducing surgeries (such as breast removal) has been associated with significant levels of anxiety and distress where careful information processing has been inhibited (Cameron & Reeve, 2006; Dillard et al., 2017). It is believed that this processing could be a factor when individuals are making treatment decisions (Denberg, Melhado, & Steiner, 2006) as studies have found individuals hold perceptions of greater benefit to treatments to reduce the risk of cancer (Cameron & Reeve, 2006; Dillard et al., 2013).

Pre-diagnosis anxiety has been linked to lower knowledge and more openness to the range of different treatment options (Dillard et al., 2017). In addition, for certain groups, the distress experienced in the cancer early detection period may be exacerbated by their lifestyle choices or circumstances and presents a need to develop skills to self-manage and cope effectively and to improve the experience (Brocken et al., 2012). Therefore, it is important to explore the opportunities and development of interventions to provide support to enable effective management during the cancer early detection period.

Men and cancer

Men are 25% more likely to develop and die from cancer than women (Clarke et al., 2013; NCIN, 2015; White, 2009; White et al., 2013; Walsh et al., 2016), with male cancer deaths equating to 33% compared to 20% in women (Ferlay et al., 2013). Bowel, lung and prostate cancer are the three most common types of cancer diagnosed in men (Cancer Research UK, 2017a). In Western countries, prostate cancer is more prevalent than other cancer, and men who are diagnosed are more likely to develop psychological distress or similar problems (Bill-Axelson et al., 2011; Ferlay et al., 2015). However, unlike other cancers, there is no national screening programme to detect prostate cancer, which remains controversial (Barry, 2008; 2009). Asymptomatic men can request to have a blood test for prostate problems called a prostate specific antigen (PSA) test carried out through their General Practitioner (GP). PSA is a protein made in the prostate gland and if some of the PSA leaks into the blood it can be measured in the PSA test. PSA levels can be higher due to several conditions, such as prostatitis. A raised PSA level does not necessarily mean the presence of cancer, and a PSA level within normal range does not mean the absence of cancer. A Digital Rectal Examination (DRE) may also be used where healthcare professionals feels the prostate via the rectum (Macmillan Cancer Support, 2018). Prostate cancer is diagnosed with DRE, PSA blood test, and Trans-Rectal Ultrasound Scan and needle Biopsy (TRUS-B) (Macmillan Cancer Support, 2018).

Research studies have identified that 40% of male cancer deaths can be linked to modifiable factors (such as lifestyle or low health service use), compared to 25% for female deaths (Danaei et al., 2005). It is well documented that men generally have poorer health outcomes than women (Wilkins, 2011) although reasons for this disparity are not fully understood (White et al., 2013). Studies have identified wider social contributing factors, referred to as 'social determinants', of cancer risk amongst men including level of educational attainment, socio-economic status, living and working conditions (Ferlay et al., 2013; Leone & Rovito, 2013; Walsh et al., 2016; White et al., 2013). There is a general reluctance from men in lower socioeconomic groups to engage with their health, and premature death is more pronounced (Wilkins, 2013). Men in the UK are more likely than women to: be obese or overweight (NHS Information Centre, 2010); drink alcohol excessively (NHS Information Centre, 2009a); have a lack of understanding about nutrition and a poorer diet (Wilkins, 2007); smoke (Robinson & Harris, 2009), and; be less likely to use primary care services (NHS Information Centre, 2009b). The latest statistics show that on average a male in the UK will live just under 4 years less than a woman (life expectancy at birth for men is an average 79.1 years, whereas for women it is 82.8 years) (Office for National Statistics, 2015). This gap is consistent across the socio-economic groups and even wider at lower socio-economic group levels. The Men's Health Forum (2009) reports that men experience a wider social gap in health than women (Wilkins, 2007), men access healthcare services less than women (Banks, 2001; Gough, 2013; White, 2001) and present at the later stages of illness or when the illness becomes critical and they reach crisis point (European Commission, 2011).

In the field of gender studies, it is recognised that men display their masculinity, in terms of their health, in a multitude of ways (Connell & Messerschmidt, 2005; Courtenay, 2011). The use of 'masculinities' is widely accepted within the sociological field in recognition of the range of the different groups of men and the diversity associated with them (O'Brien, Hunt, & Hart, 2005). Evidence suggests that some men are more likely to conform to the historic masculine stereotype of men's perception of the need to be strong, stoic and macho (Wilkins, 2013). Men with poor lifestyles are at risk, being more likely to be obese or overweight (Wilkins, 2011, 2013). A lack of comprehension of medical terminology potentially limits the ability of some men to actively engage or consider their health. This is illustrated by the results of a study carried out in the USA which found only 5% of low income, inner city men understood the function of the prostate (and only 15% and 19% respectively understood the terms 'incontinence' and 'urinary function') (Wang et al., 2013b).

Men are less likely to seek support and listen to health messages about the signs and symptoms of cancer due to a fear of diagnosis (Cancer Research UK, 2017a, 2017b) and generally have poorer outcomes, often due to late presentation (Fish et al., 2018). A recent review identified both contextual and psychological factors associated with men's under-usage of health services, factors included: the feelings of shame and embarrassment, fear and anxiety; work pressures; and fatalism regarding accessing healthcare (Fish et al., 2015). In addition, there were perceptions of poor empathy and communication with HCPs. It is acknowledged that communication around the time of a diagnosis of cancer for men is difficult and tense (Bisson et al., 2002; Brown, Oetze, & Henderson, 2016; George & Fleming, 2004). The uncertainty and limited information results in difficulties in communication, tension and stress (Brown, Oetzel, & Henderson, 2016; Checton et al., 2012) as they are faced with a dilemma in their communication about how much to disclose to others at this stage (Lepore & Revenson, 2007). Studies have found that some men choose to keep the potential diagnosis to themselves until they have more information, others may reveal some elements (to close friends and relatives), and others may be open and share with everyone (Bloch et al., 2007; Brown, Oetzel, & Henderson, 2016).

Risky lifestyle choices make certain groups more disadvantaged. For instance, men in the Gay, Bisexual and Transgender (GBT) community have higher smoking rates than the rest of the population (Johal, Shelupanov, & Norman, 2012). There is a wealth of research that indicates that gay men are more likely to experience distress linked to "coming out", stigma and homophobia (Varney, 2010), and are more likely than heterosexual men to attempt suicide (Wilkins, 2011). They are also at risk for certain types of cancer, including prostate, testicular and colon, and are at increased risk of developing some cancers. For example, men are 17 times more likely to develop anal cancer if they have male sexual partners (Centers for Disease Control and Prevention, 2010). Perceptions of stigma and disclosure are still issues that prevent the access of services for gay and bisexual men (Walter et al., 2006).

There are cultural barriers to accessing support and help for men from Black Asian Minority Ethnic (BAME) communities (Mulugeta et al., 2017). Men's understanding and attitudes towards illness, and specifically cancer, are partly culturally constructed (Abraído-Lanza et al., 2006; Burr, 2003; Dein, 2004). Problems have been identified engaging with individuals from certain ethnic minority groups in the bowel cancer screening programme (Shankleman et al., 2014). There is a perceived stigma from certain communities and fatalistic attitudes towards cancer. Mulugeta et al (2017) highlights how researchers have failed to recognise the diversity within BAME populations and hence cancer early detection strategies are not sensitive to the cultural beliefs of UK based BAME men which may impact upon screening uptake and adherence. Beliefs about how screening affects masculinity issues in black men are observed in prostate screening literature (Blocker et al., 2006; Hughes et al., 2007; Ng et al., 2013). Black men are particularly concerned with how screening will affect sexual difficulties, perceptions of being gay, invasion of private areas. These factors are prohibitive to screening attendance (Blocker et al., 2006; Hughes et al., 2007; Ng et al., 2013). This is particularly important as black men in the UK are more likely to experience prostate cancer than white or Asian men (Cancer Research UK, 2017a, 2017b). Their lifetime risk of being diagnosed is between 23.5-37.2%, compared with 13.2-15.0% for white males. Black men also report greater fear of prostate cancer and screening, especially in relation to digital rectal examination (Consedine et al., 2008; Gelfand et al., 1995; Powell, 1994). Ahiagba, Alexis and Worsley (2017) literature review data found that masculinity issues and attitudes such as viewing a visit to the GP as unmanly need to be challenged in order to encourage more men to take up screening.

Men, cancer early detection and psychosocial issues

Psychological issues - contemplating a diagnosis

Research on men in the cancer early detection period, facing the prospective of receiving test results and potentially a cancer diagnosis, have reported a variety of results with regards to anxiety experienced during the period. A number of studies have identified that waiting for screening results is associated with increases in: intrusive thoughts about cancer (Dillard et al., 2017); avoidance and anxiety due to a fear of diagnosis (Cormier et al., 2002; Ng et al., 2013; Roumier et al., 2004); anxiety levels of high risk men (over 50 with a family history of prostate cancer) (Dale et al., 2005, Gustafsson et al., 1995; Medd et al., 2005). Stress-related reactions and anxiety have been found increasingly in patients during the cancer early detection period (Awsare et al., 2008; Ellman et al., 1989; Lu et al., 2016) and studies have found between 30-75% of all cancer patients experience some level of distress (Jacobsen, 2007; Zabora et al., 2001), with clinical anxiety and depression remaining at high levels for numerous years (Sukantarat et al., 2004).

The certainty of events can provide some individuals with a certain degree of control: the ability to understand what will happen next can be comforting and reassuring (van Ravesteijn et al., 2012). Therefore, uncertainty of future health events can further provoke and exacerbate anxiety, as illustrated by reduced anxiety levels following biopsy results even when a cancer diagnosis is given (Dale et al., 2005). This demonstrates the powerful impact of eliminating uncertainty even when the results are not favourable (Mishel, 1988; Rainey, 1985). The perceived ‘threat’ of a diagnosis can: challenge an individual’s well-being; force an individual to confront their own mortality and fragility, and; evoke uncertainty about the future (Shaha et al., 2008). Mishel (1988) conceptualises uncertainty as “the inability to determine the meaning of illness-related events…a cognitive state created when the individual cannot adequately structure or categorize an illness because of insufficient cues” (Smith & Liehr, 2003, p. 25). Therefore, it could be argued that the appraisal of uncertainty has an impact on the individual’s experience and their psychological and behavioural responses to it (Brashers, 2001; Brashers et al., 2006; Mishel, 1988; Neville, 2003). Men may experience anxiety if they appraise the uncertainty as a threat, or if viewed as an opportunity they may not seek further information (Mishel, 1988). Although there is a limited number of studies identifying the experiences and management of uncertainty during the detection stage, there have been numerous studies on the experiences and management of uncertainty in individuals with cancer (Bailey et al., 2004; Kelly, 2009; McCaughan & McKenna, 2007; Oliffe et al., 2009; Seale, 2006; Wallace, 2003; Wenger & Oliffe, 2014). One third of men diagnosed with prostate cancer experience clinical distress and more than 60% experience unmet psychological needs (Balderson & Towell, 2003; Bitsika, & Christie, 2010; Cockle-Hearne et al., 2013; Nelson et al., 2009; Sharpley, Watts et al., 2014). The early detection period of prostate cancer has been found to be critical, with high levels of stress and anxiety (Halbert et al., 2010) as men wait with uncertainty as to whether they have cancer. From the total number of prostate biopsies taken, only one third will result in a diagnosis of cancer (Zeliadt et al., 2013), but the uncertainty and limited information results in difficulties in communication, tension and stress (Brown, Oetzel, & Henderson, 2016; Checton et al., 2012).

In contrast, other studies report men experience no more anxiety than those who have never attended initial screening (Carlsson et al., 2007; Essink-Bot et al., 1998) or have attended screening on multiple occasions (Brindle et al., 2006; Carlsson et al., 2007; Wade et al., 2013). The disparity between findings concerning anxiety prevalence may be accounted for by many studies only measuring anxiety levels at one time point, usually at the time point of the initial cancer screening test (such as at the initial PSA test). Findings from studies that have measured levels at two different time points (Dillard et al., 2017; Zisman et al., 2001) have found that anxiety peaked as the time approached to learn about their diagnosis. Similar findings have also been found in breast cancer studies (Benedict, Williams, & Baron, 1994; Keyzer-Dekker et al., 2014; Lang, Berbaum, & Lutgendorf, 2009; Lang et al., 2006; Liao et al., 2008). Macefield and colleagues' (2010) prostate study used four different time points and found that the impact on anxiety was highest at the time of the biopsy, with around 20% of the study cohort described high distress and anxiety. There was a significant increase in distress at the time of the biopsy was compared with levels at the PSA test. Immediately after the negative biopsy result, the levels of distress continued to be high. Interestingly, during PSA testing, mood predicted high levels of distress and anxiety at subsequent time-points (Macefield et al., 2010).

The way in which individuals appraise a potential diagnosis has an impact on their experience. Two recent male-prevalent studies, focused on the cancer early detection period of colorectal and lung cancer, reported high levels of anxiety throughout the diagnostic stage (48.4 % lung and 40% colorectal study participants) (Wiljer et al., 2012, 2013). Across the studies, participant cohorts prioritised unmet needs as: 'signposting to further sources of information'; and 'support to manage emotional needs'. The consideration of unmet needs in relation to distress experienced by men during the cancer early detection period is important for a variety of reasons. At an individual level, it is important to identify those individuals who may need additional support early in the cancer trajectory. Wider studies have demonstrated how the immune system is impacted upon directly by anxiety and depression (Kiecolt-Glaser et al., 2002), affecting responses to and increasing risk of infections (Glaser et al., 1999; Glaser et al., 2003; Sheridan et al., 1991). Stress-related disorders, such as anxiety and depression, have been found to be linked to an increased risk of having a stroke or developing cardiovascular disease (Haines, Imeson, & Meade, 1987; Kawachi et al., 1994; Pan et al., 2011; Rutledge et al., 2006). Zhu and colleagues (2018) found a positive correlation between the experience of a stress-related mental disorder at cancer diagnosis and increased admissions for cardiovascular disease.

Therefore, it could be argued that it is imperative to consider the effect of psychological distress on service and information provision. The relationship between increased anxiety and information processing raises important points for exploration within the cancer early detection period. Wider studies evidence the association between higher anxiety and lower cognitive abilities (Hancock, 1986; Kahneman, 1973; Pilcher, Nadler, & Busch, 2002; Sauro, Jorgensen, & Pedlow, 2003) in addition to comprehension and attention (Cameron & Reeve, 2006; Lerman et al., 1995). As highlighted earlier, existing studies suggest that clinically significant levels of anxiety and distress can impair and inhibit careful information processing and are associated with: greater interest in risk-reducing surgeries; and perceptions of greater benefit to treatments related to reducing the risk of the cancer (Cameron & Reeve, 2006; Dillard et al., 2013). For example, individuals who are high in anxiety, have been found to: be interested in testing regardless of their knowledge or perceived benefits of the treatment (Cameron & Reeve, 2006). Other studies have identified association between clinically significant levels of anxiety and distress and decisions after diagnosis (Cohen & Britten, 2003; Denberg, Melhado, & Steiner, 2006), and; adherence to advice on smoking, physical activity and diet (Bultz & Carlson, 2006; Carlson & Bultz, 2004).

At diagnosis

It is accepted that a cancer diagnosis has a harmful effect on an individual's wellbeing (Gall, 2004; Rustoen et al., 1999; Taylor & Maimer, 2005). The appraisal of the diagnosis differs between individuals and can be, in part, due to certain predisposed characteristics or circumstances. Although appraisals differ, at the point in time the diagnosis is confirmed, a large number of studies have found an overwhelming surge of negative emotion is often experienced, with the most prominent emotion being anxiety (Burgess et al*.,* 2005; Dillard et al., 2017; Edwards & Clarke, 2004; Hughes, 1982; Linden et al., 2012; Saegrov & Halding, 2004; Stanton & Snyder, 1993; Stark & House, 2000; van't Spijker, Trijsburg, & Duivenvoorden, 1997).

A number of studies have found that stress and blame, associated with stigma, are common experiences of people affected by cancer (Conlon et al., 2010; Else-Quest et al., 2009; Gulyn & Youssef, 2010; Holland, Kelly, & Weinberger, 2010; Vodermaier, Esplen, & Maheu, 2010). Cancer is still a taboo for many men and viewed by some as a death sentence (Avery et al., 2008; Bancroft et al., 2015; Ferrante, Shaw, & Scott, 2011; Fyffe et al., 2008; George & Fleming, 2004). As individuals are programmed to preserve themselves (Rosenblatt et al., 1989), men taking actions to avoid confrontation with their own vulnerability and mortality protect their self-esteem and reduce anxiety (Rosenblatt et al., 1989). But if the thoughts and feelings are not externalised it can lead to depression and reduced mental health (Li et al., 2009; MacDonald & Anderson, 1984; Markowitz, 1998; Quinn & Chaudoir, 2009; Simbayi et al., 2007).

This evidence presents important consideration for future interventions with regards to the capacity of individuals to take on board and retain information. Previous studies of men with cancer have shown persistently that anxiety about the diagnosis has a tendency to interfere with how they process information in relation to risks and benefits of treatment (Denberg et al., 2006; Zeliadt et al., 2006). Therefore, the timing of support and education about the options for treatment may be critical as research on decision making in prostate cancer (Ramsey et al., 2009; Zeliadt et al., 2010) confirm that the majority of patients arrive at a treatment decision rapidly following diagnosis with the majority only considering one option. Research has shown that partners or significant others have an important role in accessing and engaging with information, liaising between the healthcare professionals (and the individual undergoing diagnostic testing) and supporting future choices of potential treatments (Echlin & Rees, 2002; Hubbard et al., 2010; Xu et al., 2011). Feeling uncertain about the best course of action to take may fuel and perpetuate emotional responses (Houldin, 2003). It is well documented that individuals who have difficulty tolerating uncertainty are at greater risk of negative effects and various forms of psychopathology (Frenkel-Brunswik, 1951; Hajek, 1991; Hajek, Belcher, & Stapleton, 1987; Linehan, 1993; Simons & Gaher, 2005). The stigma associated with cancer means that some men are at heightened risk of perceived devaluation, as they perceive they are viewed as ‘different’ and not as valued by others in society, which can result in stress and distress (Major & O’Brien, 2005). For example, a recent study suggested that the threat of cancer can be perceived as threatening the ability to work; with the prospect of physical weakness (from the treatment) which is linked to feelings of ‘a loss of manhood’ (Ettridge et al., 2017). For such men, there is opportunity for services to target men at diagnosis, and at greater risk of negative affect, to provide support to manage psychological distress. Evidence suggests that being connected and having strong social support can be particularly beneficial for people affected by cancer from diagnosis (Bloom, Petersen & Kang, 2007; Forsythe et al., 2014; Foster & Fenlon, 2011) into recovery and onto survivorship (Forsythe et al., 2014; Foster & Fenlon, 2011).

Social support issues

Research indicates that having a partner is a key influencing factor regarding men’s health: unmarried men are less likely than married men to receive PSA testing (Walter et al., 2006). Partners of men have been found to: act as a source of support and persuade their male partner to visit the GP or proactively seek information about their health (Men’s Health Forum, 2014); protect against the minimalizing or deterioration of social networks (losing touch with family especially in later life), and; reduce the chances of social isolation in later life (Johal, Shelupanov, & Norman, 2012). In connection, Berger and colleagues (2012) identify that men are unlikely to seek medical help when disconnected or isolated from key contacts (such as work, family, community), as routine and social connectivity provide stability and act as a buffer against isolation whilst still preserving a sense of belonging, important to masculine identity (Berger et al., 2012). This may be due to a lack of primary relationships that support and encourage health seeking behaviours (Cohen, Gottlieb, & Underwood, 2000).

Men with good social support have been found to have improved coping, self-management and health related quality of life (Kershaw et al., 2008; Scholz et al., 2008). Conrad and White (2010) highlight that men may rely more heavily on smaller social support networks, trusted safe spaces for talking are restricted, and men are more reluctant (than women) to share feelings of vulnerability (Conrad & White, 2010). Men feel vulnerable when faced with the prospect of loss without having the protection of social connections to provide support, a strategy frequently used by women (Möller-Leimkühler, 2003). Therefore, becoming widowed, separated or divorced poses a major risk for social isolation and loneliness, as men are more likely to reduce their contact with close family (Ghate, Shaw, & Neal, 2000). Studies have shown links between isolation and a greater risk of: cognitive decline (James et al., 2011), lower self-esteem (Steptoe et al., 2004) and depression (Cacioppo et al., 2006); defective immune functioning and higher blood pressure (Grant, Hamer, & Steptoe, 2009; Hawkley et al., 2010); and suicide in later life (O’Connell et al., 2004). Consequently, strong social connections, including family and friendships (Richmond, Law, & Kay-Lambkin, 2011), have a significant impact on life expectancy, improvements in health and quality of life (even after accounting for factors such as smoking, gender and ethnicity) (Holt-Lunstad & Layton, 2010). Being connected is likened to the cumulative effect of giving up smoking, healthy eating, and lowering blood pressure and cholesterol (Hawkley et al., 2010; Holt-Lunstad & Layton, 2010).

During the cancer early detection period, being able to identify individuals who may be more at risk of developing heightened anxiety (and intolerance of uncertainty) with low social support, provides an opportunity for targeted intervention. For such men, awaiting confirmation of results and a final diagnosis will be stressful, as will ongoing surveillance (Brocken et al., 2012). There is opportunity for healthcare services to risk-stratify men to ensure that those who need support are made aware of, and referred to, evidence-based strategies to address unmet needs and manage psychological distress.

Men, cancer early detection period and opportunities for intervention

Lifestyle advice and support

Changing lifestyle habits and health behaviours is important for men being tested for cancer, as strong evidence exists for the link between obesity, smoking, alcohol consumption, sedentary lifestyles and increased risk of developing cancer (Parkin, Boyd, & Walker, 2011). Recent research (World Cancer Research Fund International, 2014) found that men who are overweight or obese have an increased risk of developing advanced prostate cancer. Many men in the cancer early detection period exhibit risk factors (Hackshaw-McGeagh et al., 2015), but the general public have low levels of understanding about the link between lifestyle and cancer risk (Cancer Research UK, 2008, 2017b; Stead et al., 2012). The Wanless report (2004) set out the need for individuals to be engaged with their health, and the Darzi Review (Department of Health, 2008) focused on strengthening the role and impact of ill health prevention. Following a study demonstrating the benefits of a healthy lifestyle in providing a 14-year increase in life expectancy (Khaw et al, 2008), the NHS Future Forum (2012) recommended that healthcare organisations should incorporate the promotion of healthy living into their daily interactions with patients.

In line with the Health Belief Model (Rosenstock, 1974), cancer-related events, such as the interaction between a healthcare professional and patient attending a screening appointment, is viewed as an opportunity for a brief intervention and behaviour change conversations (Demark-Wahnefried et al., 2005) often referred to as a ‘teachable moment’. The NICE guidance (2014) on individual approaches to behaviour change outlines that behaviour comes about from an interaction between an individual’s ‘capability’ to perform a behaviour, and the ‘opportunity’ and ‘motivation’ to carry it out. A change in one of these components is needed to create either a change in behaviour or new behaviour. This theory is referred to as the COM-B model (referring to Capability, Opportunity, Motivation and Behaviour model) (Michie, van Stralen, & West, 2011). Research investigating interventions based on the ‘teachable moment’ concept have reported some effectiveness in instigating behaviour change within the screening field, mainly within colorectal screening (Baker & Wardle, 2002; Caswell, Anderson, & Steele, 2009; Craigie et al., 2011; Robb et al., 2010; Senore et al., 2012). Craigie and colleagues’ (2011) study showed significant behaviour change through weight loss by targeting diet and physical activity behavioural change strategies with CRC screening and motivational interviewing.

Healthcare professionals have a public health duty to highlight to their patients the lifestyle risk factors associated with unhealthy practices (NHS Future Forum, 2012), but there are still a number of barriers to discussions about changing lifestyle behaviours (Anderson et al., 2013; Coa et al., 2014). There is concern that when advice is lacking it may be viewed as endorsement of the behaviours (Anderson et al., 2013; Larsen et al., 2007). Typically, there is a lack of male specific studies within this area, and also a lack of understanding around the optimum time for intervention (Williams, Steptoe, & Wardle, 2013). Timing is an important consideration, as existing studies suggest that clinically significant levels of anxiety and distress can affect adherence to advice on smoking, physical activity and diet (Bultz & Carlson, 2006; Carlson & Bultz, 2004). However, as personal growth and positive cognitive revisions (following rumination) are also potential consequences of distress (Miles et al., 1999), it could be argued that it is an optimal time for intervention (Frankl, 1986). Studies from the psycho-oncological field have reported the potential for positive changes and growth as a result of experiencing challenging life events (Scrignaro, Barni, & Magrin, 2011; Stanton, Bower, & Low, 2006). From this perspective, an experience of cancer has the potential to stimulate positive psychological changes in an individual's self-perception, social relationships and priorities; this is referred to as Post-Traumatic Growth (PTG) (Calhoun & Tedeschi, 2006; Joseph & Linley, 2005, 2008; Tedeschi & Calhoun, 1996).

Self-management support

Self-management support interventions benefit a wide variety of cancer survivors (Cockle-Hearne & Faithfull, 2010; Preyde & Synnott, 2009; Wilson, 2008) and in recent years there has been a growth in the development of studies supporting the positive psychosocial outcomes specifically for men with cancer (Heiniger et al., 2017; Martin et al., 2013; Weber & Sherwill-Navarro, 2005; Wootten et al., 2015). Evidence is therefore growing for the effectiveness of self-management support interventions targeting men (Galdas et al., 2015). However, the number of men willing or able to access and engage with self-management support interventions remains limited (Chodosh et al., 2005; Furler, Harris, & Rogers, 2011; Kennedy et al., 2013). Recent studies have shown that the acceptability of self-management support interventions targeting men can be enhanced when the context, content, and delivery style is bespoke to the valued aspects of male identities (Galdas et al., 2014; Hunt et al., 2013; Hunt et al., 2014a; Hunt et al., 2014b; Robertson et al., 2014).

Kiselica and Englar-Carlson (2010) outline a masculinity-positive psychology framework, and argue that the approach should be a fundamental part of any therapeutic work with men. A strength-based approach is potentially more attractive to men because it aligns with the notion of building on existing qualities and strengths, and emphasises pragmatic problem solving and specific outcomes (Kiselica & Englar-Carlson, 2010; Padesky & Mooney, 2012). Padesky and Mooney (2012) developed a four-staged strengths-based cognitive behavioural therapy (CBT) model to support the building of positive qualities and strengthening personal resilience. The model is founded on the principle that there are many different routes to building resilience, and that individuals have a number of bespoke strengths that when built on will encourage resilience to filter into other aspects of their life. Carlson and Englar-

Carlson (2008) liken the approach to building courage and bringing awareness to those strengths, which can bring a sense of belonging and hope for the future (Carlson & Englar-Carlson, 2008). Building resilience - the ability to recalibrate a personal worldview in relation to cognitions, beliefs and behaviours (Walsh., 2016) - in individuals enables them to cope with the challenges of everyday life, persist when difficult circumstances occur, and face the adversity of serious life-threatening events (Walsh., 2016). Resilient individuals have the ability to accept when situations cannot be changed (Bonanno, Wortman, & Nesse, 2004). One of the advantages resilience brings is that it acts as a buffer and shields individuals from the potential mental and physical outcomes of stressful events (Rutter, 1985; Yi, Vitaliano, & Smith, 2008).

Applied positive psychology theory and research, often associated with Seligman and Csikszentmihaly (2000), is based on the concepts of well-being, happiness and human flourishing. It has been established for several decades and is founded on a strength-based approach. Following the attention given to it by Seligman and Csikszentmihaly (2000), a rise in the evidence base of positive psychology approaches and particularly the efficacy of interventions was witnessed. This evidence relates to: identifying and practicing expressing gratitude (Seligman et al., 2005; Sheldon & Lyubomirsky, 2006); establishing goals (Green, Oades, & Grant, 2006; Sheldon et al., 2002); practising kindness (Otake et al., 2006); and; using personal strengths (Seligman et al., 2005). Positive psychology techniques have been part of CBT for some time (Linley & Joseph, 2004). CBT is well placed to support people to harness their positive qualities and skill. Treating people experiencing a range of difficulties (such as anxiety and depression) using Cognitive Behavioural Therapy (CBT) approaches is effective and well evidenced (Beck, 2005; Butler et al., 2006; Chambless & Ollendick, 2001; Cuijpers et al., 2013). Karwoski and colleagues (2006) suggest there are multiple benefits to combining the two approaches as they encourage: the reappraisal of thoughts and coping strategies; relaxation and mindfulness training; identifying pleasant activities and problem-solving skills and; a focus on goals. Goal setting is fundamental to both hope theory (Snyder, 2000) and self-efficacy theory (Bandura, 1977) both commonly used to theoretically underpin self-management interventions (Carmack et al., 2006; Lepore et al., 2003; Martin et al., 2013; Weber et al., 2004). Hope theory recognises wider goals and behaviours, across situations (Snyder, 2000) whereas self-efficacy theory focuses on specific goals and behaviours (Bandura, 1977) and emphasises the role of agency beliefs.

Galdas and colleagues' (2014) systematic review identified several optimal conditions and facilitators to increase the acceptability and accessibility of self-management support interventions targeted specifically for men. The first recognised value, or construct, is the ‘need for purpose’, to have clear structure and focus on taking action to address an unmet need. Secondly, the space created for the exploration of issues needs to be one that men can trust and feel supported within: this is especially important for sensitive taboo topics such as cancer (Galdas et al., 2014; Oliffe et al., 2010). In addition, men value the lived experiences of their peers, because the opportunity to share with others brings a sense of belonging and normality (Cramer et al., 2014; Dickerson et al., 2011; Gooden & Winefield, 2007; Oliffe et al., 2010; Sullivan, 2003). Finally, there is great value in interventions that build on the strengths men already have and the acknowledgement of the expertise (by experience) that they bring (Galdas et al., 2014). The accrued knowledge and information gained, via the lived experience, is important and needs to be fully recognised as it gives men confidence, identity and value. Therefore, interventions need to be focused on instrumenting change, aligned with masculine ideals (Corboy, McDonald, & McLaren, 2011). Within the context of cancer, it is imperative to understand the accessibility and acceptability of self-management support interventions for men. Therefore, the optimal conditions - referred to as ‘constructs’ - that Galdas and colleagues (2014) propose for men with wider long-term conditions will be explored further within the oncology self-management support intervention field.

Construct 1: Need for purpose

Support that is centred around obtaining new information, or a skill, is appealing for men with cancer. Cognitive-behavioural therapy (CBT) has been positively linked with the effectiveness of an intervention and has been shown to be an optimal approach (Cockle-Hearne & Faithfull, 2010; Molton et al., 2008; Penedo et al., 2004; Penedo et al., 2006; Penedo et al., 2007). The mechanism of cognitive restructuring has been identified as a core reason for using cognitive behavioural techniques with men (Brooks, 2010; Primack et al., 2010). The effective components include: problem solving (Mishel et al., 2002); relieving uncertainty (Stiegelis et al., 2004); developing coping strategies (Stiegelis et al., 2004), and; cognitive reframing (Mishel et al., 2002). The use of reframing and cognitive restructuring has been found to be beneficial and effective for men in several oncology studies, including watchful waiting (Bailey et al., 2004) and increased benefit finding (Pascoe & Edvardsson, 2016) for prostate cancer. Orom and colleagues’ (2015) study identified how CBT could effectively support newly diagnosed men with low optimism and resilience associated with distress.

Building resilience and flexibility, through practising mindfulness, has also provided positive changes for men with cancer as the ability to be psychologically flexible has been associated with better psychological outcomes (Chambers et al., 2016). Recent studies of men’s experiences of mindfulness, have found reductions in anxiety and avoidance (Chambers et al., 2012; Victorson et al., 2016), uncertainty intolerance, and mental health (Victorson et al., 2016). Through the practice of core components, mindfulness encourages self-awareness and presence in the moment, offering relief from frequent rumination and anxiety (Jain et al., 2007; Lykins & Baer, 2009; Ramel et al., 2004). Mindfulness particularly encourages consideration and less impulsive reactions to experiences, and recent studies have linked outcomes from mindfulness interventions to self-control, acceptance, personal growth and self-regulation (Dobkin, 2008; McKenzie et al., 2007).

In line with a need for a clear purpose, action orientated activities and practices are attractive to men (Galdas et al., 2014). Cockle-Hearne and Faithfull's (2010) review of men with prostate cancer aligns with this construct, highlighting the most important issue is to target intervention components to men's specific needs to gain greater relevance for participants. They found that men are more likely to engage with an intervention, and feel most motivated, when the intervention is relevant to the issues they are facing.

Construct 2: Trusted environment

Creating a safe space for the exploration of issues and an environment that men can trust and feel supported within is especially important for sensitive taboo topics such as cancer (Galdas et al., 2014; Oliffe et al., 2010). Fostering an environment where men feel supported and able to participate may be nurtured through several approaches. Self-management support interventions that engender trust (such as through cancer support groups or online forums) provide a platform for many men to disclose sensitive issues (Oliffe et al., 2010), such as difficulties around sexual function, and gain support from peers within a safe space. Social context variables, such as social support, lead to successful cognitive adjustment to trauma by facilitating the re-evaluation of the meaning of trauma through dialogue and reframing, enabling emotional adaption (Lepore, 2001). If the trauma is discussed in a compassionate social context, such as a face-to-face support activity or group, there is the potential to learn and understand through others. The impact is an increased awareness of how negative emotional responses can be replaced with positive ones, leading to an increased sense of control responses. By hearing about others' coping mechanisms and acceptance of circumstances, individuals are more open to be able to cognitively process the trauma by facilitating a desensitisation towards thoughts and ruminations about the cancer threat (Lepore, 2001). Through shared experience, a sense of hope is instilled, reducing a sense of isolation and increasing knowledge about the experience, with a consequence being the increased awareness of potential coping strategies (Legg et al., 2011; Moulton et al., 2013; Ussher et al., 2006). Despite acknowledging the benefits of a shared experience, a recent study on men with prostate cancer, identified barriers to group or shared support (Chambers et al., 2018). These included a belief that support groups just focused on psychological and emotional issues, feeling uncomfortable to share in a group context and the death of group members.

However, other previous studies have shown a relationship between attending a cancer related social support group and positive outcomes, such as improved coping skills, quality of life, elevated mood and self-worth (Gottlieb & Wachala, 2007; Grande, Myers, & Sutton, 2006; Trapp et al., 2013). The therapeutic advantage of group support builds a narrative, creating a structure around the experience (Chambers et al., 2018; Mattingly, 1994). It could be argued that group support builds resilience for the future. Creating a narrative around an experience is part of the process of group support, enabling the individual to create their own sense out of the experience. Commonality of experience and additional non-clinical information offers support and alleviates anxiety with a shared knowledge of mastery and confidence (Krumwiede & Krumwiede, 2012). However, studies on face-to-face group interventions have also highlighted the detrimental outcomes for individuals witnessing the effects of progressive deterioration in those individuals who are further along the disease trajectory (Salzer, 2002).

Other approaches to creating a trusted environment include shared activities such as sports (Hunt et al., 2014a; Hunt et al., 2014b) or expressive writing (Pauley, Morman, & Floyd, 2011, Rosenberg et al., 2002). Writing has been found to be particularly beneficial to men during ongoing stressful events affiliated with cancer (Pauley, Morman, & Floyd, 2011, Rosenberg et al., 2002). From concentrating and writing about positive aspects relating to the stressful event, reported outcomes (compared with control groups) have included improvements in self-reported mental health (Pauley, Morman, & Floyd, 2011), less pain and healthcare service utilisation (Rosenberg et al., 2002). The effects have been found to be sustained at 3 and 6 months after the intervention (Rosenberg et al., 2002). There may be potential benefits of this intervention for those men who have difficulty communicating their feelings or sharing with others.

Construct 3: Peer support

Peer support is a valued part of self-management support interventions for men (Galdas et al., 2014), defined as “the provision of emotional, appraisal and informational assistance by a created social network member who possesses experiential knowledge of a specific behaviour or stressor and has similar characteristics as the target population” (Dennis, 2003, p. 329). The multiple benefits of peer support for people with an array of cancer diagnoses are gaining momentum (Campbell, Phaneuf, & Deane, 2004; Dickerson et al., 2011; Dunn et al., 2003; Gooden & Winefield, 2007; Hoey et al., 2008; Oliffe at al., 2010; Sullivan, 2003) not only for self-management but also for de-stigmatisation (Verhaeghe, Bracke, & Bruynooghe, 2008); quality of life and social functioning (Resnick & Rosenheck, 2008). Peer support has been found to help men express their experiences of illness, and share knowledge and thoughts, making them feel less isolated (King et al., 2015). The opportunity to share with other men has been found to be empowering and to provide a sense of meaning in men's experience of cancer (Galbraith, Hays, & Tanner, 2012; King et al., 2015) even when the information provided is not positive (Krumwiede & Krumwiede, 2012).

Peer support within cancer care has a positive impact on psychological well-being, rebuilding hope and aiding decision-making (Meyer, Coroiu, & Korner, 2015). The importance of social relationships and being connected to others is illustrated by the positive impact it has on mortality and recovery (Dennis, 2003). Robertson et al.’s (2015) recent study concluded that peer support is a preferred option (over professional-only support) for many men, as it is viewed as unobvious help-seeking. However, for peer support to be effective for men it needs to ensure it embraces gendered identities (Seebohm, Munn-Giddings, & Brewer, 2010).

Peer support within cancer care has been taken on in different forms, including one-to-one support and groups led by peers or HCPs (Broom, 2005; Carter et al., 2011; Chambers et al., 2012; Ervik, Nordoy, & Asplund, 2010; Galbraith, Hays, & Tanner, 2012; Matsunaga & Gotay Cook, 2004; Milne, Spiers, & Moore, 2008; Nanton et al., 2009; Nanton & Dale, 2011; O’Brien et al., 2010; Ream et al., 2009; Wallace & Storms, 2007; Walsh & Hegarty, 2010). The delivery of peer support interventions within cancer support varies; however, the majority include discussion groups. Prostate cancer peer support interventions (Lepore, 1999; Weber et al. 2004, 2007) have demonstrated improvements in mental health outcomes (depressive symptoms) when compared with controls. By nature of being a ‘fellow peer’, the approach offers a ‘parity of esteem’ that is not possible through professional support (Dunn et al., 2003; Faulkner & Kalathil, 2012). Therefore, peer support through the ‘lived experience’ offers a forum for a bespoke form of empathy with others (Dunn et al., 2003; Faulkner & Kalathil, 2012) and can help to build self-efficacy, a sense of mastery to achieve desired goals (Bandura, 1997), and improve health outcomes (Lorig & Holman, 2003). It helps to regulate the impact of stress on health as it disrupts the relationship between stress and distress (Aneshensel, 1992; Dohrenwend, 2000; Pearlin, 1999). The importance of social relationships and being connected is illustrated by the positive impact it has on mortality and recovery (Dennis, 2003).

Having the opportunity to talk to others with cancer, who have been through the same or a similar experience, has found to be reassuring (Krumwiede & Krumwiede, 2012). Robertson et al.’s (2015) recent study concluded that peer support is a preferred option (over professional-only support) for many men with long-term conditions, as it is viewed as unobvious help seeking. Knowledge by experience is significant and recognized as an important, central element, to optimum care delivery (Coulter, 2002; Forbat et al., 2009) and at the leading edge of policy and practice reform (Barello, Graffigna & Vegni, 2012). However, for peer support to be effective for men it needs to ensure it embraces gendered identities (Seebohm, Munn-Giddings, & Brewer, 2010) aligning support with men’s need for independence, strength and self-reliance.

Social support has an impact on the relationship between coping and health outcomes, but it is not currently understood how, or what kinds of social support self-management activates (Paterson, Robertson, & Nabi, 2014; Zhou et al., 2010a, 2010b). The use of peer support to engage with individuals considered to be difficult to reach (such as men from BAME and GBT communities) has been studied across health issues (Sokol & Fisher, 2016) and found to be effective, and successful, due in part to the trust and respect that is engendered within the process.

Construct 4: Becoming an expert

The ability to receive information and build knowledge to effectively manage and cope to become an ‘expert’ is important to men with cancer (Arrington, Grant, & Vanderford, 2005; Bell et al., 2010; Dickerson et al., 2011; Evans et al., 2007; Gooden & Winefield, 2007; Martin et al., 2013; Oliffe et al., 2010; Oliffe et al., 2011; Seale et al., 2006; Sullivan, 2003). Accruing information and being aware enables men to feel in control. In Krumwiede & Krumwiede’s (2012) prostate study, men reported how having increased information and knowledge gave them a sense of security, even if the information was negative. Being prepared and understanding the possibilities gave the men in the study reassurance. Information and knowledge are important to men during the cancer early detection period (Wiljer et al., 2012, 2013) and they use numerous sources to gain it, including their social network, the healthcare team and the internet (Wiljer et al., 2012, 2013). There is evidence to suggest that a common coping mechanism used when faced with the possibility of bad news is the notion of psychological ‘buffering’ or ‘bracing’ to mentally prepare for the negative outcome. In the same way as a physical buffer, this is activated to provide protection and cushioning in a proactive preparatory way to ‘soften the blow’. This is exacerbated when the outcome is considered harmful, imminent and has negative repercussions (Shepperd, Sweeny, & Carroll, 2006; Taylor & Shepperd, 1998).

Men’s health, masculinities, gender and help seeking

In Western cultures, dominant hegemonic masculine ideals of stoicism and strength (Courtenay, 2009) have dominated the narrative around men’s reluctance to access help and health care in a timely manner (Galdas, 2009). The common theme, in research studies, portrays men as reluctant to engage in help seeking for health (Nekolaichuk et al., 2011; White & Banks, 2004; Wilkins et al., 2008), or accessing health services (Wang et al., 2013a; Smith et al., 2005) in comparison to women. However, although differences are recognised and acknowledged (Sullivan, 2003), the research is variable with regards to help seeking for cancer in men, and women, with other studies showing comparatively small differences (Lyratzopoulos et al., 2012; Macleod et al., 2009; Smith et al., 2005; Wang et al., 2013a). For instance, a study across three cancer tumour sites (colorectal, lung and malignant melanoma) found little evidence of men being diagnosed later than women or any gender difference in GP consultation rates in the two years before the confirmed cancer diagnosis (Wang et al., 2013a). Increasing consideration is being given to the similarities of men and women’s accounts, and the variation of the way masculinity is expressed, in relation to help-seeking (Farrimond, 2011; Galdas, Cheater, & Marshall, 2007; Galdas et al., 2010; Johnson et al., 2012; O'Brien, Hunt, & Hart, 2005; Townsend, Wyke, & Hunt, 2006; Townsend, Wyke, & Hunt, 2008). A range of studies have highlighted the variation and contrast between men and masculinities within the context of help seeking and health (Galdas, Cheater, & Marshall, 2007; O’Brien, Hunt, & Hart, 2005; Robertson, 2006). Connell’s (1995) work recognizes the concept of multiple masculinities that reflect the social diversity of men related to factors such as: ethnicity, sexuality, age and social class. In addition, Galdas and colleagues (2005) identifies the notion of ‘male socialization’ as having an adverse effect on men’s help-seeking and emphases its complexity, and multifaceted nature, as men negotiate a range of masculine identities influenced by these factors (age, ethnicity and socioeconomic status) (Galdas, Cheater, & Marshall, 2007). Research acknowledges that men categorised by marginalised masculinities, based on these factors, can have poorer health outcomes than men in other groups. For example, research conducted with men in Canada found that prostate cancer may have a greater impact on Black African Canadian men, compared to White Canadian men, due to its impact on virility which is perceived to be an important cultural aspect of affirming masculinity (when other resources or opportunities are limited, such as a highly paid career) (Evans et al., 2005).

A rise in contemporary research emphasizes help seeking as fluid and transient, across men and women’s accounts, determined more by cultural moral frameworks and notions of ‘responsibility’ than by gender (Llanwarne et al., 2017; MacLean et al., 2017). A recent gender comparison study in lung cancer detection (Maclean et al., 2017) challenges binary gender stereotypes of ‘stoical men’ being more reluctant to attend consultations and ‘anxious women’ attending with minor issues, demonstrating that both genders need support, arguing the need to go ‘beyond the masculine-feminine binary’ (Galdas et al., 2010, pg 6).

Therefore, with regards to the cancer support needs of men, and women, the picture is complex and multidimensional. Some studies have found differences in the support needs of men and women with cancer (Sullivan, 2003), and the language used to express the emotion experienced (Gooden & Winefield, 2007), whilst other studies have found limited differences with numerous similarities (Gooden & Winefield, 2007; Boudioni et al., 2001). To a similar extent, both men and women have been found to engage with two styles of support: informational and emotional (Gooden & Winefield, 2007; Boehmer & Babayan, 2005) both identifying the need for information on specifics related to: tumour-type; credible published booklets about targeted therapies; and emotional support (Boudioni et al., 2001). However, gender comparative studies remain uncommon, with limited studies comparing men and women with similar morbidity (Annandale et al., 2007, Hunt, Adamson, & Galdas, 2010) and the need for more critical research is recognised (Hunt, Adamson, & Galdas, 2010). The growing recognition that both men and women express a need for informational and emotional support during the cancer early detection period highlights that more research is needed to understand the fuller broader picture of the similarities and differences, to inform policy, practice and intervention development. Future researchers need to go beyond applying just a gender sensitive approach to understanding the fuller picture of the similarities and differences between men and women, and between men, and must include broader determinants that influence health, such as ethnicity, age, and socioeconomic factors, alongside help seeking and support.

Optimising the accessibility of self-management support interventions for men

Evidence of the most beneficial method to deliver interventions to men with cancer is equivocal and uncertain (Cockle-Hearne & Faithfull, 2010). Men with cancer have found benefit in both group sessions and one-to-one involvement (Cockle-Hearne & Faithfull, 2010) and the way in which men with cancer choose to access self-management support is multifaceted. A growing area is the ability to access self-management support remotely or using self-directed approaches (Beatty, Koczwara, & Wade, 2011; Duffecy et al., 2013; Leykin et al., 2012; van den Berg et al., 2013). The approaches are gaining momentum in order to increase the accessibility of support and address the specific needs of men (Chambers et al., 2015; Nanton et al., 2018; Schover et al., 2012). Zwahlens et al.’s (2017) recent study identified that one of the main reasons why patients turned down psycho-oncological support is due to a preference for self-help, to be able to manage effectively independently. These findings align with previous studies (Clover et al., 2015; Neumann et al., 2010) indicating the preference of individuals with cancer, experiencing high levels of distress, for self-help to access support independently and to manage effectively by themselves.

The ease of access and anonymity of gaining support, and information, through internet-based interventions is attractive to men and is a growing area within cancer care (Beatty, Koczwara, & Wade, 2011; Duffecy et al., 2013; Leykin et al., 2012; van den Berg et al., 2013). The outcomes from online interventions appear to be equal, in some studies, to traditional face-to-face delivery as illustrated by Schover and colleagues' (2012) randomised control trial that demonstrated equal benefits between attending a psychotherapeutic intervention with a psychologist or accessing the intervention online. In addition, there are multiple benefits to using technology-based interventions to reach populations that might not engage with traditional health or support services. Online interventions aimed at health outcomes (ehealth) offer a cost-effective alternative to face-to-face interventions, and allow for new ways to evaluate and assess outcomes (Ritterband et al., 2009). There has been a recent rise in the development and implementation in the behavioural healthcare field, including mobile phone-based (Armstrong et al., 2009; Brendryen & Kraft, 2008; Crankshaw et al., 2010; Kunutsor et al., 2010; Shet & de Costa, 2011) and web-based interventions (Brendryen, Drozd, & Kraft, 2008; Dallery & Raiff, 2011; Strecher, Shiffman, & West, 2005; Titov, 2007; van Straten, Cuijpers, & Smits, 2008).

Recent internet use in the 65-74 age group has increased from 52% (in 2011) to 78% in 2017, with men in that age group more likely to use the internet than women (ONS, 2018). There has been a sharp rise in retired, economically-inactive adults using the internet (ONS, 2018). E-health interventions have been found to minimise the stigma of help-seeking for men after a diagnosis (Wootten et al., 2014), are accessible at any time, and offer anonymity. The additional benefit of online support is that it offers an opportunity to overcome barriers to uptake of support (such as isolation and stigma) (Nanton et al., 2018; Wootten et al., 2014).

Research into online interventions for people affected by cancer is gaining more attention (Beatty, Koczwara, & Wade, 2011; Duffecy et al., 2013; Leykin et al., 2012; van den Berg et al., 2013), but much of the work relates to the stage after treatment. Nevertheless, the effectiveness of mental health online interventions has been well documented (Barak et al., 2008; Griffiths, Farrer, & Christensen, 2010). Brief internet interventions have been found to be effective for delivering online mental health services with improvement for participants receiving as little as four brief 5 -10 minute interventions (with a focus on sleep, thoughts, activity level, and assertiveness) (Bunge et al., 2016). Improvements have been experienced through decreases in depression and anxiety levels (Ahmedani et al., 2015; Ayers, Fitzgerald, & Thompson, 2015; Bunge et al., 2016; Ondersma et al., 2005, 2007, 2011, 2012, 2014) and improvements in their mood, motivation and confidence (Bunge et al., 2016). Interestingly, studies report more improvement with three or more brief modules on depressive scores (Bunge et al., 2016; Christensen et al. 2006).

There is opportunity to build on previous work and look with a ‘gender lens’ at the needs of men during the cancer early detection period, as previous studies indicate the powerful effect derived from sharing experiences and feeling connected (Atherton, & Ziebland, 2017; Naslund et al., 2015; Newhouse, Ziebland & Wyke, 2012). Men seek health information and gain support from the internet and learn about other people’s experiences of facing illness. There are multiple benefits to be gained, including: a sense of empowerment to be able to make informed decisions (Entwistle et al., 2011); reduced isolation and confidence by managing expectations (Lowe et al., 2009). A shared sense of camaraderie and group identity has been found to reduce uncertainty and build self-efficacy (Brewer, 1991; McKenna & Bargh, 1998). Supportive web-based social interactions with peers can improve illness experiences and support self-management in ways that are hard for individuals to negotiate offline, by, providing access to support that is faceless and perceived as private) (Allen et al., 2016).

Identifying the problem

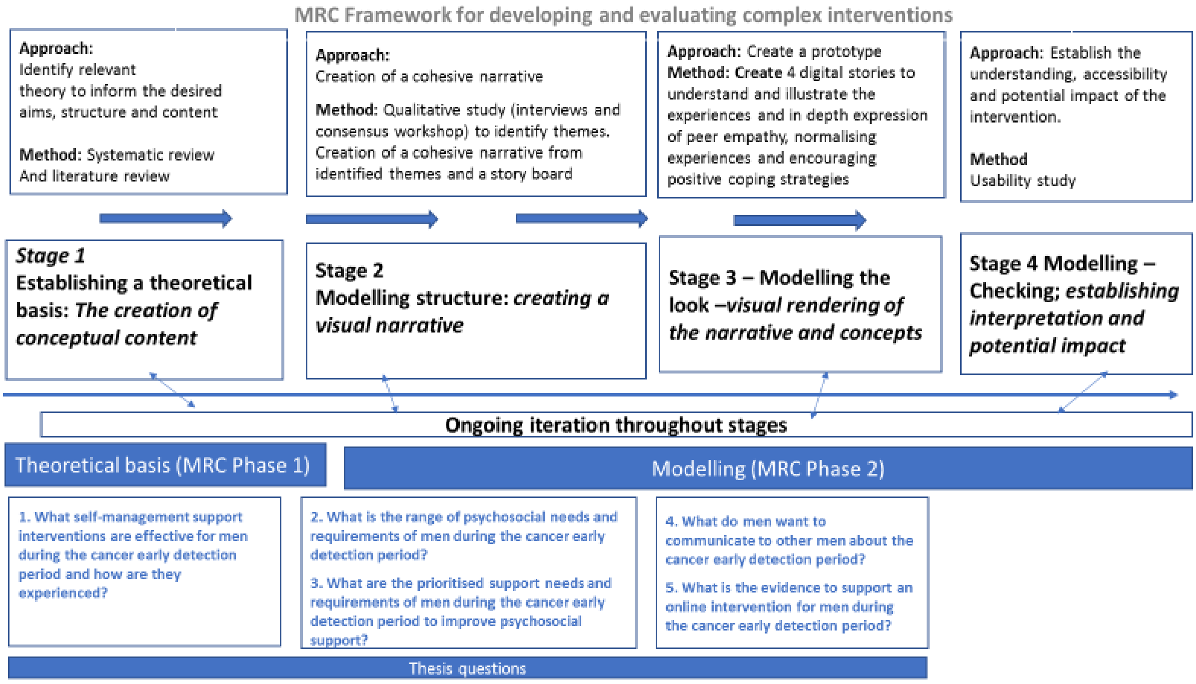
Cancer incidence rates are due to rise by 2035 (Smittenaar et al., 2016) and as the number of people affected by cancer increases (in line with current trends), there will be more men living with uncertainty and heightened anxiety. Although the cancer early detection period has been acknowledged as a distressing time, the work in this area has concentrated primarily on breast, gynecological and prostate ‘watchful waiting’ screening periods (Awsare et al., 2008; Lebel et al., 2003; Zisman et al., 2001). It is recognised that there is still insufficient research looking at the period of waiting (Irving, 2001; Lang et al., 2009) in other cancers and particularly identifying, and addressing, the unmet needs of men. Despite studies showing that early detection period has the potential to affect both diagnosis and post-diagnosis periods (Drageset & Lindstrøm, 2005; Widerman, 2004), it is still largely unknown what long-term implications these heightened levels of anxiety and unmet needs have.

The process of identifying those patients most likely to have significant problems in the future (referred to as ‘risk stratification’), and providing intervention early is an attractive prospect that could inform future commissioning of cancer services (Watson et al., 2012). It is well documented that there are wider factors that impact on men’s experience of distress post diagnosis, such as the level of social support (Spendelow et al., 2018). For example, married men who have lots of support from their partners experience less distress than those who are unmarried or whose spouses offer little support (Kamen et al, 2015). There is also growing evidence (Perry et al., 2017) to suggest that a cancer diagnosis may influence an individual’s personality. For example, recent research indicates that neuroticism and introversion are linked to an increased likelihood of experiencing depression, general emotional distress, and suicidal ideation in prostate cancer (Perry et al., 2017), suggesting that emotional distress is shaped by an individual’s personality. It is proposed that collaborative care-managed psychosocial interventions could target unhelpful thoughts, and the way individuals interact with the world. A recent study evidenced the link between those with severe stress-related responses during the cancer early detection period and an increase in hospital admissions (Zhu et al., 2018). Identifying those men who may need more support than others earlier on in the cancer trajectory offers potential longer term benefit as it is recongised that certain factors could influence the success or compliance with treatment recommendations (Watson et al., 2012). Therefore, this under-researched area provides opportunities to enhance patient experience, and the potential to affect clinical outcomes and health economics for some groups (Zhu et al., 2018). There is a need for further investigation regarding what self-management support interventions are effective for men during the cancer early detection period, and how they are experienced by them. The next chapter aims to identify specifically targeted studies, through a mixed methods systematic review.

Developing a complex intervention

The Medical Research Council framework for the development and evaluation of complex interventions offers a robust step-by-step mechanism to aid researchers in identifying key appropriate methods and evidence (Craig et al., 2008). The framework enables a robust approach to be taken. The structured approach ensures each stage is explicit for the researcher and gives a degree of assurance for future replication and evaluation. An intervention’s complexity is determined by several factors, namely: the number of components, the interactions between those components, the targeted group, behaviours and flexibility involved with implementation (Craig et al., 2008). The MRC framework (Craig et al., 2008) (see Figure 3) highlights the developmental stage as an important process involving the identification of evidence and theoretical base to support the intervention, detailing the process and outcomes, and laying the important foundations before it is piloted for feasibility (Craig et al., 2008). Each chapter starts with an outline of the stage in the framework it relates to and explicitly sets out the link between the stage, approach taken and the method, as Figure 3 illustrates:

Figure 3 - MRC Framework for developing and evaluating complex interventions



Assumptions and underpinning of the research

Research paradigm

The research in this thesis is underpinned by a range of assumptions and approaches. The aim of the exploratory research was to develop a solution that can be applied to an existing problem, acknowledging the contexts in which they emerge (Madill, 2007). The epistemological approach to the research is based on critical realism (Bhaskar, 1975) which argues that experiences are conditioned by the beliefs and perceptions that individuals hold. It recognises that natural events are easier to witness and analyse empirically, because social ones are more complex (Bhaskar, 2010; Scott, 2007). Thus, there may be different interpretations of objective reality viewed through subjective individual perspectives. The critical realist approach acknowledges the importance of both subjectivity and objectivity, and therefore fits well with a range of research methods (McEvoy & Richards, 2006). In line with the aim of this exploratory research, a mixed methods approach, combining qualitative and quantitative methods, was chosen to explore the experiences of the early cancer detection period, and the research questions posed (Plano Clark & Creswell, 2008; Thøgersen-Ntoumani, Fox & Ntoumanis, 2005).

Theoretical frameworks

Identifying theory-based research, in addition to evidence-based research, is important for a comprehensive inclusive approach, to establish a thorough understanding of the issues of the focused study. This comprehensive approach will guide the design and development of the studies and subsequent intervention, thereby assisting future replication and allowing for comparison with other studies (Linden, Butterworth, & Roberts, 2006; Linden & Roberts, 2004).

For the purposes of this thesis, the theoretical framework needs to incorporate the special conditions involved with men waiting for cancer test results. There is a need for a framework that encapsulates the antecedents, identified needs and coping strategies of men within the cancer early detection period. There are a number of theories that include the transactional processes involved with the assessment and appraisal of stress and coping that could be used to guide the studies (Heider, 1958; Lazarus & Folkman, 1984; Leventhal, Meyer, & Nerenz, 1980).

Attribution theory is one model that, if applied to the context of the cancer early detection period, provides a rationale for how individuals may interpret the stage as stressful and the effect it has on thoughts, emotions and behaviour (Heider, 1958). However, this model is limited in its scope and does not take into consideration the wider context of antecedents, coping strategies and outcomes. Self-regulation theory (Leventhal, Meyer, & Nerenz, 1980) incorporates the coping elements of managing an event perceived to be stressful. In relation to applying the theory to the cancer early detection period, it takes into consideration the appraisal aspect of interpreting the threat of cancer, the potential consequences and how controllable the outcome might be, whilst incorporating coping strategies and the adaption of outcomes. The theory does not include the psychosocial components of appraisal and coping during the stages, and therefore does not give the full picture of the components which account for the experience.

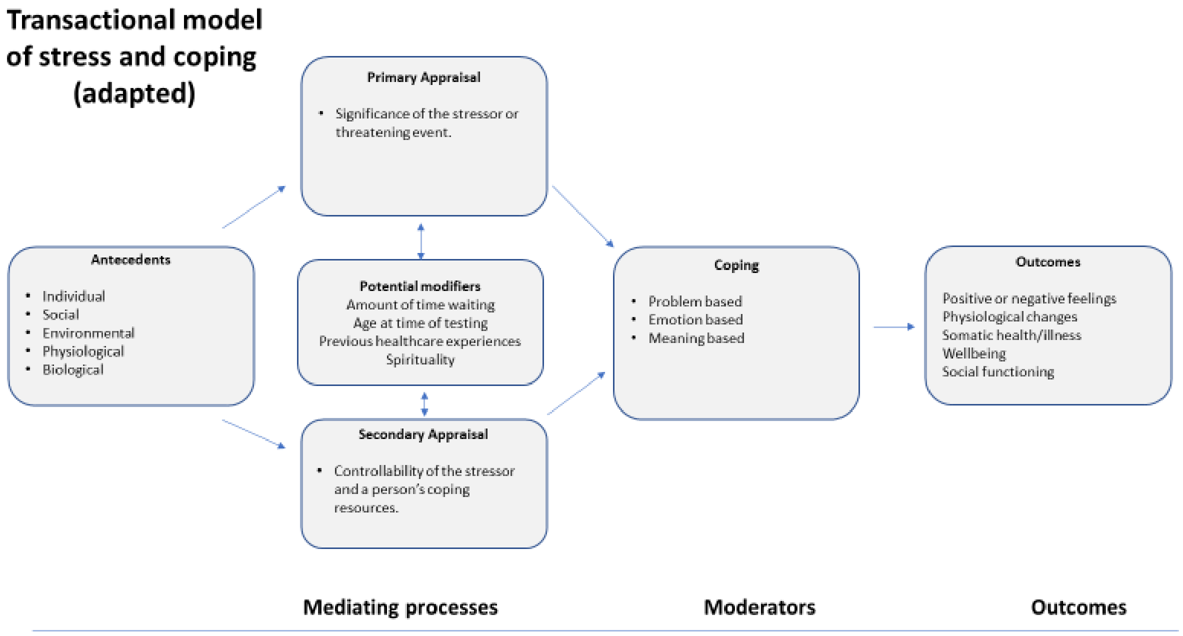
According to Lazarus and Folkman's transactional theory of stress and coping (Lazarus, 1999; Lazarus & Folkman, 1984), a combination of cognitive appraisals (an individual's subjective feelings and thoughts), and their coping strategies and emotional responses result in individualised differences in outcomes to perceived stressful events. Lazarus and Folkman (1984) original model proposed problem-focused and emotion-focused coping as the two main strategies used by individuals when they encounter stressful situations. Problem-focused coping is an attempt to control the stressful situation, whereas emotion-focused coping is a process used by avoiding the stressful situation or cognitively reconstructing the context. Studies have demonstrated that both problem-focused and emotion-focused coping strategies are used by patients with cancer (Lavery & Clarke, 1996) and there is a selective use of specific coping strategies among certain groups. The model incorporates continual reappraisal (via feedback loops) as further attempts to cope subsequently impact reappraisal of coping potential and outcomes.

The original model (Lazarus & Folkman, 1984) underwent significant theoretical development, with additional components incorporated, during the 1990s (Lazarus,1991,1993,1999). An identified weakness of the original model (Lazarus & Folkman, 1984) was the restricted concept of appraisal. During *primary* appraisal, the event is appraised as irrelevant, benign-positive or stressful. The initial two appraisal types - irrelevant and benign-positive - do not need any further action such as a coping response, whilst the latter ‘stressful’ appraisal does. The types of ‘stress appraisals’, in the original model, were limited as either perceptions of ‘threat, harm, and challenge’, with no inclusion of different appraisal combinations or acknowledgement of how emotions acted as a moderator. It focused on the regulation of distress, with positive emotion usually only contemplated when the aversive conditions of the distress stopped i.e. the experience of relief. However, subsequent research gave recognition to the co-existence of positive and negative emotions during the stress, and coping process, observed through studies with participants enduring ongoing chronic stress (Folkman, 1997; 2008). During ongoing events, such as a long-term illness (endured over a substantial period with no foreseeable end), positive emotions were recorded. Through her studies, Folkman (1997; 2008) identified two areas for further development including: positive emotions within the stress and coping process; and the role of coping processes in facilitating positive emotions during the stressful circumstances. As a result, a strength of the updated model was that the concept of appraisal was broadened out to incorporate an individual’s assessment of: goal relevance and congruence; perceived coping potential; responsibility appraisals; and, evaluation of the expected stress or longevity. In addition, the revised version incorporated the range of defined appraisal combinations, including a variety of emotions such as: anger, guilt, fear/anxiety, sadness, hope/challenge, and happiness, surprise, resignation, tranquillity, shame/humiliation, interest, boredom, and relief (Lazarus, 1999).

Within the original model (Lazarus & Folkman, 1984), cognitive reappraisal was determined by the success of coping efforts. Outcomes that were viewed as successful resulted in positive emotions, however failure to gain a resolution from the situation resulted in distress, requiring further appraisal and coping attempts. This applied a limited lens to cognitive reappraisal and restricted its applicability to a real-world context (Folkman, 1997; 2008). A strength of the revised model (outlined in Figure 4) is the acknowledgment that unsuccessful coping and any subsequent distress has the potential to trigger meaning-focused coping (especially when the perception of the stress is uncontrollable). Meaning focused coping (assessing values, beliefs, and goals, attaching positive meaning to ordinary events) was incorporated into the later model (Lazarus, 1999) in recognition of its impact on positive emotions. Meaning focused coping can provide resources that influence appraisals, support coping efforts across time, and alleviate distress by providing ‘relief’ (Folkman, 2008).

Therefore, to underpin the research in this thesis, the revised model is used as it provides a more rounded and comprehensive version of the conceptual framework of Lazarus’s transactional theory of stress and coping (Lazarus, 1999; Lazarus & Folkman, 1984) (as illustrated in Figure 4).

Figure 4 – Transactional model of stress and coping



The model states that coping strategies are dependent on the context experienced by individuals (Dunkel-Schetter et al., 1992). However, there is a paucity of studies applying the model to the cancer early detection period. Men during the cancer early detection period undergo exploratory procedures and consequently emotional adaptation and re-adaption. Therefore, a fundamental aspect of this thesis is to explore men’s appraisal (and reappraisal) of the early detection period, the coping strategies they employ, the effectiveness of the strategies used, and the outcomes. A number of factors have been found to influence positive coping of cancer patients, including social support (Bourjolly & Hirschman, 2001), marital satisfaction (Weihs et al., 1999), religious resources (Gall et al., 2000), and social problem-solving abilities (Nezu et al., 1999). However, there has been limited examination of stress and coping during the cancer early detection period, with an insufficient focus on men.

Thesis structure

The identified questions that the thesis will address are:

1. What self-management support interventions are effective for men during the cancer early detection period, and how are they experienced? (Chapter 2)
2. What is the range of psychosocial needs and requirements of men during the cancer early detection period? (Chapter 3)
3. What are the prioritised support needs and requirements of men during the cancer early detection period to improve psychosocial issues? (Chapter 4)
4. What do men want to communicate to other men about the cancer early detection period? (Chapter 5)
5. What is the evidence to support the content of an online intervention for men during the cancer early detection period? (Chapter 6)

The structure of the thesis is outlined as follows. This initial overview and background chapter aims to gain a wider understanding of the issues and needs of men in the cancer early detection period (including risk factors and vulnerability to psychological morbidity and help seeking) and exploration of male-specific interventions targeting support during other stages of the cancer trajectory. Chapter 2 presents a mixed methods systematic review of interventions to support men during the cancer early detection period. The aim of the chapter is to explore the evidence from studies undertaken, with a view to identifying the effectiveness of interventions to address identified needs. As the few studies that have focused on the cancer early detection period are limited to a couple of tumour sites (and mainly prostate cancer detection), a mixed methods design was chosen to explore the issues in more detail. Chapter 3 details the qualitative semi-structured interview study designed to understand the range of important issues that affect men during the cancer early detection period. The prioritisation workshop, outlined in Chapter 4, was designed to rank - in order of highest need - the most important issues that affect men during the period. The depth and detail of the data, outlining men's experiences (in Chapter 3) and prioritising need (in Chapter 4) enabled a focus novel approach to be taken for the final study in Chapter 5. The novel arts-based approach taken to chapter 5, via the co-design of digital stories, illustrate four participant's narrative accounts of the cancer early detection period and detail the participant's evaluation of the process and the impact. Chapter 6 proposes an online peer support intervention, developed within a theoretical framework and built on a positive psychological strengths-based approach. It is grounded in the experiences of men who have been through the cancer early detection period and structured to exploit components that have an effective evidence base. Chapter 7 brings the discussion together and makes recommendations for future research, services and policy based on the findings of this understudied area of research.

Conclusion

This chapter has presented an overview of current understanding in relation to the experiences of men during the cancer early detection period. It has highlighted the prevalence of distress in men during the cancer early detection period (Awsare et al., 2008; Ellman et al., 1989; Lu et al., 2016) and the potential impact on future outcomes (Denberg et al., 2006; Dillard et al., 2017; Drageset & Lindstrøm, 2005; Paskett, Harrop, & Wells, 2011; Widerman, 2004). Relevant theories and concepts associated with the development of a proposed online self-management support intervention have been examined and a theoretical framework for the thesis has been outlined. The potential consequences of distress and unknown needs of men during the cancer early detection period, in addition to the lack of evidenced-based provision of support for men, has highlighted a need for further intervention research in this area. It is not clear what interventions exist for men during the cancer early detection period and how men experience using them. The following chapters of this thesis aim to understand these identified gaps.

Chapter 2 – A mixed methods systematic review to examine the effectiveness of self-management support interventions aimed at men during the cancer early detection period

Introduction

The previous chapter presented a comprehensive narrative review of the wider literature in relation to the broader context of the cancer early detection period and the experiences of men with cancer. The wider causes, consequences and prevalence of psychosocial issues for men have been set out, and the chapter highlighted the limited understanding of the psychosocial processes linked with the experiences of men during the cancer early detection period. A lack of clarity around the interventions, and their outcomes, was identified for men during the cancer early detection period even though the fluctuating prevalence of distress in men during the cancer early detection period was acknowledged (Awsare et al., 2008; Ellman et al., 1989; Lu et al., 2016). The potential consequences of distress and unknown needs of men during the cancer early detection period, in addition to the lack of evidenced-based provision of support for men, highlighted a need for further research in this area. It is important to understand the evidence to be able to inform and direct future intervention research on the cancer early detection period, to target the most effective intervention components for integration into future designs. Therefore, the findings from Chapter 1 determined the need for a more detailed comprehensive systematic review of the literature to identify what self-management support interventions are effective for men during the cancer early detection period, and how they are experienced. This is the aim of this chapter.

During the cancer early detection period, men awaiting the results of cancer tests report experiencing high levels of anxiety due to uncertainty, with some cases of levels higher than after a diagnosis of cancer (Dale et al., 2005). Although recognized as one of the most stressful periods of the cancer journey (Fridfinnsdottir, 1997; Lebel et al., 2003; Poole, 1997; Poole & Lyne, 2000), limited knowledge exists regarding understanding the support needs of men during the period from test completion to obtaining the results (Irving, 2001; Lang, Berbaum, & Lutgendorf, 2009).

Recent studies have found that cancer survival in the UK is lower than the European average for many cancers, and detecting cancer early has the greatest potential for improving the outcomes and survival of cancer patients (Cancer Research UK, 2017a, 2017b; Foot & Harrison, 2011). Recently the National Cancer Transformation Board outlined a range of steps designed to support early detection, speed up diagnosis and improve the experience of patients in the published ‘Achieving World Class Cancer Outcomes: Taking the strategy forward' (NHS England, 2016b). The strategy outlined the introduction of a new 28-day faster diagnosis standard, designed to ensure that patients find out within 28 days whether, or not, they have cancer. Full uptake of the standard is expected by 2020 (NHS England, 2016b). The rise in advancements within the cancer early detection period, such as the ability to detect cancer at the earliest stage via a blood test (Uttley et al., 2016), will accelerate the need to understand patient experiences including how patients can be supported effectively. In 2015, NICE introduced new guidance (NG12) (NICE, 2015) for the management of suspected cancer on the urgent 2-week wait (2WW) cancer referral pathway; included in the updated guideline is the recognition of the lack of current research on patient information needs and patient experience throughout the cancer diagnostic pathway. It recognises that filling the gap should improve future patient experience and calls for more qualitative studies to be published to highlight the need to assess the key issues in patient experience and information needs in the cancer diagnostic pathway (NICE, 2015). In line with the recognised deficit in the NICE (2015) guidelines, there is a need to understand what support interventions are effective and understand the experiences of patients during the diagnostic period to inform early detection guidelines, practice and policy.

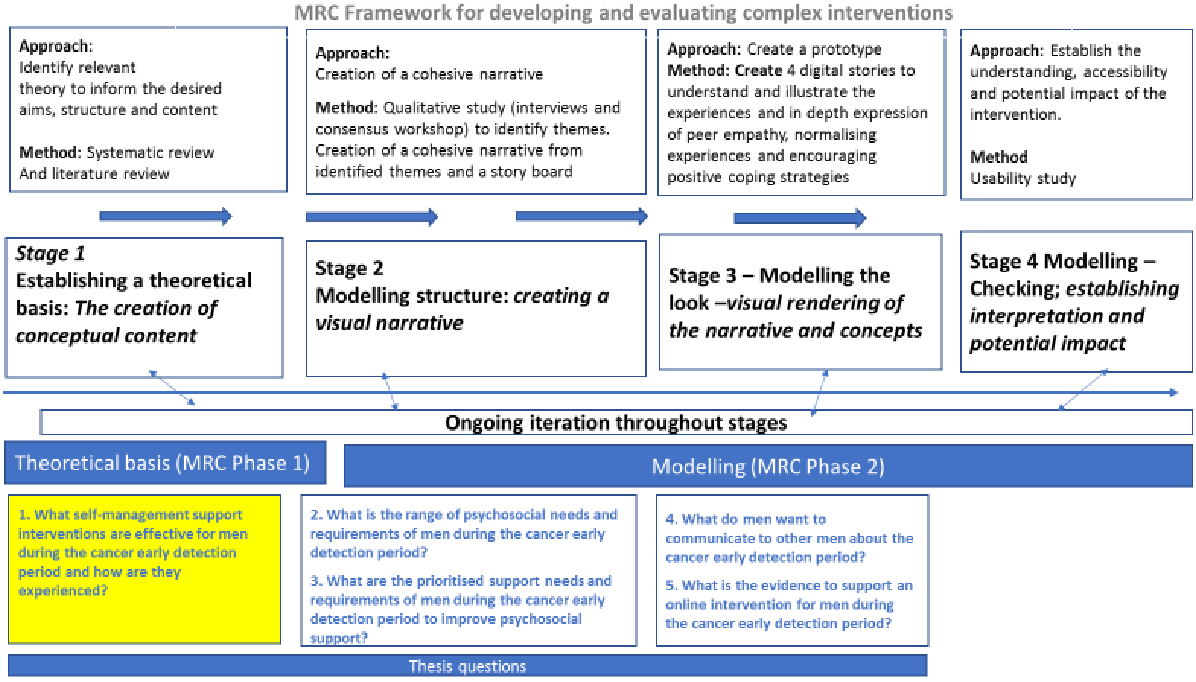
Therefore, although there is growing evidence for the effectiveness of self-management support interventions to benefit a wide variety of cancer survivors (Cockle-Hearne & Faithfull, 2010; NCSI, 2013; Preyde & Synnott, 2009; Wilson, 2008) and specifically for men with cancer (Heiniger et al., 2017; Martin et al., 2013; Weber & Sherwill-Navarro, 2005; Wootten et al., 2015) it is not yet known what interventions are effective for men facing the potential of cancer during the early detection period. Also, it is not yet known what outcomes are associated with these interventions, and how users experience them. It is important to understand this evidence to be able to inform and direct future intervention research, focused on the cancer early detection period, and provide evidence on the most effective intervention components - specifically for men - for integration into future designs. This mixed methods systematic review aims to identify and aggregate the self-management support interventions that exist for men during the cancer early detection period, to assess the quality and gain evidence of gaps for further research (Estabrooks, Field, & Morse, 1994). An initial scoping of the literature identified a plethora of studies aimed at providing self-management support interventions (as outlined in Table 1) - mainly adherence to screening attendance - in the cancer early detection period (before testing). Yet there has been no systematic review examining the existing studies on the period once cancer testing has occurred but before the test results have been confirmed.

Table 1. Categories and descriptions of self-management interventions and support activities

(Galdas et al., 2014)

As detailed earlier in Chapter 1, the UK Medical Research Council Framework for the Development and Evaluation of Complex Interventions (Craig et al., 2008) provides structure for each stage and study throughout the thesis (see Figure 5). This mixed methods systematic review builds on the foundations of Chapter 1 and seeks to further develop the fundamental process of Phase 1, Stage 1 of the Framework, to understand the evidence of existing interventions aimed at men during the cancer early detection period. Therefore, in line with the framework, this mixed methods systematic review will help to answer the question relating to what self-management support interventions are effective for men, including the outcomes and experiences associated with them.

Figure 5: MRC Framework Phase 1 – Stage 1



The objectives of this systematic review are to identify the effectiveness of self-management support interventions designed to support men (over the age of 18 years old) during the cancer early detection period, and capture evidence in relation to the outcomes associated with the use of the interventions. Close attention is paid to these dynamics and the focus is on the following research question to advance knowledge, research, and practice related to identified needs during the cancer early detection period:

Review question: What self-management support interventions are effective for men during the cancer early detection period, and how are they experienced?

Methods

This mixed methods systematic review was interested in understanding the effectiveness of self-management support interventions aimed at men during the cancer early detection period. The outcomes and experiences of users who received an intervention were of interest. Therefore, incorporating both qualitative and quantitative studies enabled a greater understanding of the whole picture (Mays, Pope, & Popay, 2005) to inform future research (Hagger, 2009, 2010). To ensure that the review met the objectives outlined, the review followed the method for systematic reviews of Joanna Briggs Institute (JBI, 2014) for both qualitative and quantitative research and reported using the Preferred Reporting Items for

Systematic Reviews and Meta-Analysis (PRISMA) (Moher et al., 2009). A meta-analysis was planned to be completed if included studies equated to more than one RCT, with participant homogeneity (explicit outcomes and results separated for male participants if a mixed gendered cohort was included) and intervention homogeneity criteria met (in line with Table 1). Quantitative data included in the meta-analysis used pre-and-post test data using Cohen's d (to indicate the standard difference between two means) and 95% confidence intervals (CI). The synthesis of qualitative and quantitative findings were presented separately initially and then transformed into a final synthesis using a results-based convergent synthesis design (Hong et al., 2017). The methodological approach chosen enabled qualitative enquiry to be synthesised alongside quantitative research to determine how the intervention was experienced (its usefulness and why it worked - or did not work - for participants). The review searched literature, written in English, from January 2000 until November 2017.

Protocol and registration

The protocol for this systematic review has been registered with PROSPERO (Appendix 1). The systematic review process used the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidance (Moher et al., 2009) and can be viewed in Appendix 2.

Searching and identification

The search strategy was produced following an initial scoping of the literature in relation to providing self-management support interventions, during the cancer early detection period, focused on men. Aligned with good practice (Machi & McEnvoy, 2016), the initial scoping aided the identification of key words and phrases which were integrated into the search strategy, refining it to ensure that the terms entered produced relevant papers (Centre for Reviews and Dissemination, 2009). Key words and phrases were combinations aligned with the three main variables in the review: self-management support interventions (psychological, psychosocial, behavioral, psychoeducation, peer support, navigation); cancer early detection period (early diagnosis, diagnostic tests, asymptomatic screening) and males (gender, men). Truncations were used where categories were expanded to improve the sensitivity of the search and identify any differences in the search terms used. Each specific subset of terms was aligned with Boolean logic and joined with 'OR', each specific subset was then combined with 'AND' to facilitate the approach. The search strategy was adjusted to ensure that it fitted the variety of syntax, subject and MeSH headings used by the databases to facilitate the search.

A systematic search was conducted using the following electronic databases, covering the period from 1st January 2000 to 30th November 2017: MEDLINE, CINAHL, Web of Science, PsycINFO, Cochrane library, and the Cochrane Database of Systematic Reviews. To ensure a comprehensive search, multiple databases were used, as recommended (Abdulla & Krishnamurthy, 2016). A secondary search of grey literature was searched from National Health Service Bowel Cancer Screening Programme. A manual backward snowball search was completed by examining the reference lists of the included studies to enhance the process. Papers that were available as full text in English were included. See Appendix 3 for an example search using CINAHL.

Screening and exclusion criteria

All articles retrieved from database searches were exported and duplicate articles were removed. Studies were initially systematically screened by title and abstract to identify relevant articles which included a relevant self-management support intervention. After initial assessment, full papers were then retrieved and further screened against the inclusion criteria, until a final selection of papers was checked for accuracy. Articles that did not match the inclusion criteria were discarded. The development of the eligibility and exclusion criteria was formed from the research questions. In line with the Centre for Reviews and Dissemination (CRD) guidelines (CRD, 2009) the following PICOS criteria was included:

	Inclusion	**Exclusion**
Population	Sample with > 49% men over 18 years old	Sample participants not over 18 years old Sample not male or mixed gender sample is not explicit by gender (or male sample is less than 49% of sample).
	Participants must be in the cancer early detection period between testing and confirmation of diagnosis	Participants at different stages of cancer trajectory
Interventions	Study includes self- management support intervention (as outlined in Table 1)	Study does not include a self-management support intervention (in line with Table 1)
Comparisons	Study with or without comparison	N/A
Outcomes	Study includes quantitative or qualitative outcomes and experiences relating to intervention use. Outcomes of interest include the effect of interventions on anxiety measures, QOL, knowledge, awareness and understanding.	Study does not have explicit outcomes relating to the samples experiences of the self-management support intervention
Study design	Intervention only (quantitative or qualitative)	Not an intervention – cross sectional, observational, qualitative experiences not about intervention
Other	Studies written in English Published after 1st January 2000 Published studies and grey literature	Not written in English Not published after 1st January 2000 Focus of study not the cancer early detection period

Data collection and risk of bias assessment

The study details (aim, sample details, methodology, analysis, outcomes) were extracted by one reviewer (AL) using the MASrARI data extraction instrument from JBI-NOTARI (Pearson, 2004) (See Appendix 4 for tool). The table of study characteristics (Table 2) was populated with data extracted from the papers. Authors were contacted as necessary to clarify information. The risk of bias tool for across studies was taken into consideration and included bias of reporting selected outcomes, language and time lags. The risk of bias for each individual study was conducted using a methodological rigour tool developed by Hawker and colleagues (2002), enabling the assessment of rigour for mixed methods, quantitative and qualitative intervention studies (Table 4).

Data extraction and quality assessment

The data was extracted using a standardised abstraction matrix (Long & Godfrey, 2004). Appraising the quality within and across the studies is an essential component to this systematic review. The Critical Appraisal Skills Programme (CASP) tool was used to assess the quality of the components of selected papers, including the aims, design, methods, data analysis, interpretation, findings and value of the research (CASP, 2013, 2016). The Mixed Methods Appraisal Tool (M-MAT) designed by Pluye and colleagues (2009) was used to evaluate the methodological quality across the studies. It is a reliable tool for quality assessment specifically designed for use in systematic reviews that include qualitative, quantitative and mixed method studies. The tool (see Appendix 5) enables mixed methods studies to be assessed using design-specific criteria. The quality assessment, scored as a percentage, explored whether the research methods were pertinent to the questions.

Data synthesis

Data from the included quantitative and qualitative reviews were initially analysed separately.

1. **Quantitative**

   A meta-analysis was planned to present mean difference in anxiety levels, reflecting the mechanism by which distress is monitored. However, meta-analysis was not possible due to high heterogeneity (clinical and methodological) in the quantitative studies, including incomplete datasets. Therefore, descriptions of study characteristics, outcome measures, and key findings are presented.

2. **Qualitative**

   The qualitative data underwent an initial segregated analysis using inductive data-driven thematic analysis (Braun & Clarke, 2006). Thematic analysis was used to identify, describe, analyse and report patterns and themes within the data and followed the six-phase process by critical reflection (see Appendix 6) (Braun & Clarke, 2006).

3. **Mixed methods**

   A convergent qualitative synthesis analysis was used to convert quantitative and mixed-method findings into qualitative ones, creating a mixed methods synthesis (Pluye & Hong, 2014) in tabular format. Columns and rows held the data, and a summary was developed in the table, giving equal weight to both the quantitative and qualitative data. Additionally, themes were identified by an inductive process (Patton, 1990) through analysis of the summary findings. Additionally, using the quantitative analysis, a narrative synthesis was undertaken using the Practical Systematic Review of Self-Management Support for long-term conditions (PRISMS) taxonomy to categorise components of self-management support (Pearce et al., 2015).

Results

A total of 991 studies were identified from the search strategy, with 199 duplicates removed. After evaluation of the title and abstracts, 77 papers remained for full text eligibility assessment. Figure 6 presents the screening process diagrammatically. The remaining three papers were assessed for methodological quality and remained included for synthesis (Chiu et al., 2016; Wade et al., 2015; Zeliadt et al., 2013). The backward snowball searches of the reference lists of the studies retrieved did not produce additional studies that satisfied the inclusion criteria.

Figure 6. PRISMA Flowchart

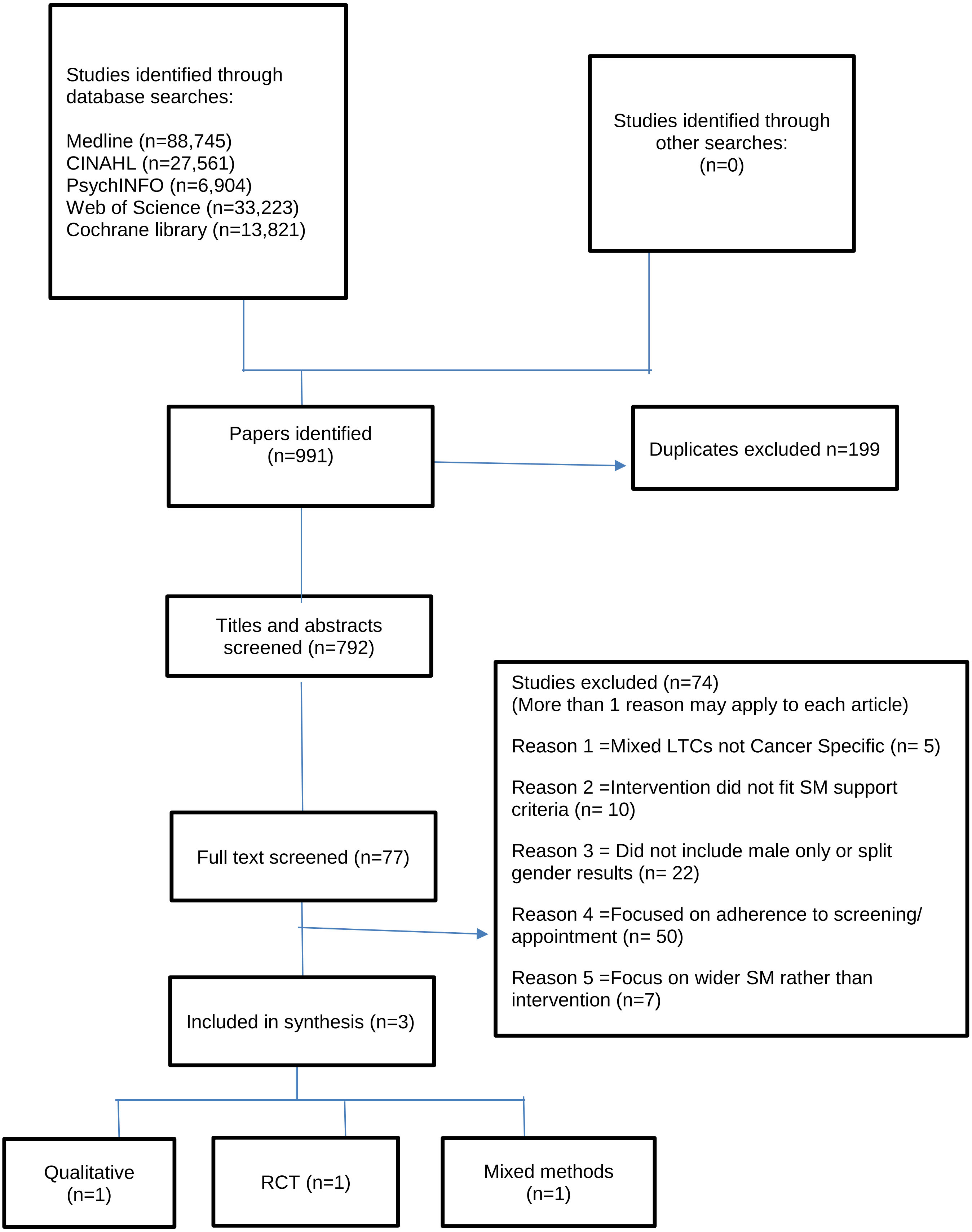


Table 2. Study overviews and characteristics

Study	**Classification**	**Tumour site**	**Research Design**	**Sample**	**Intervention summary**	**Measures used**	**Outcome measures**	**Results/ group differences over time**	**Quality score**
Zeliadt et al., 2013, USA	Health education	Prostate	Mixed Methods	29 Men. (18 – ED 11-UC) Mean age 65 yrs, 17 white, 10 married, 5 college or graduate degree, 5 went onto to have a positive biopsy result.	1.Educational (ED) packet (biopsy instruction sheet with a booklet about the biopsy procedure). 2.Prostate cancer treatment decision aid	Stewart's Interpersonal Processes of Care Instrument (16 item) Control Preferences Scale Decisional Conflict Scale (10 item) Assessment of Patients' Experience of Cancer Care (5 item) Memorial Anxiety Prostate Cancer scale PHQ-8 (Patient Health Questionnaire) Descriptive analyses summarized the findings of the semi-structured interview items assessing use of the materials	Utilization of educational materials. Prostate cancer knowledge. General depressive symptoms Prostate cancer specific anxiety. General quality of life, and processes of care at the baseline interview for all participants, as well as at post-biopsy follow-up. At follow-up evaluation, men with positive biopsy results received additional cancer-related measures.	Anxiety scores were similar for both groups while awaiting the biopsy procedure, with anxiety scores trending lower in the ED group: 41.2 on a prostate-specific anxiety instrument compared to 51.7 in the UC group (p=0.13). ED participants reported **better overall quality of life** while awaiting biopsy compared to the UC group (76.4 vs. 48.5, p=0.01). The small number of men in the ED group who went on to be diagnosed with cancer reported being **better informed about the risks and side** effects of each option compared to men diagnosed with cancer in the UC group (p=0.07). Men reported they found the pre-biopsy materials to be helpful and indicated having information about possible treatment options **reduced their anxiety**. However, 2 of 18 men reported they did not want to think about treatment options until after they knew their biopsy results.	75%
Wade et al., 2015, UK	Health education	Prostate	Qual semi struct ints	85 Men. Mean age 63.6 yrs, 84 white.	1.Biopsy patient information leaflet 2.Face-to-face clinical consultation (CNS or clinician)	In-depth qualitative interviews were conducted after biopsy result was known a median of 10 and 18 weeks following biopsy, and within the ProtecT study, a median of 41 weeks after biopsy. Interviews were by telephone or face-to-face in each man's	Levels of preparedness Impact of unanticipated TRUS-Bx experiences Information provision improvements	Pre-biopsy information provision plays a key role in determining how men experienced biopsy, how well prepared they were and potentially had more influence than the severity of their symptoms. Anxiety arose when symptoms deviated from pre-biopsy information. Men responded to anxiety by contacting health professionals for reassurance and most received reassurance rather than active treatment. Men suggested that improvements to pre-biopsy information (reflecting the severity effectively) would **help men effectively prepare and manage, reduce anxiety and avoid unnecessary consultations.** Information provision is essential in enabling men to discriminate between minor and	50%

						preferred location. Interviews were semi-structured using a topic guide.		serious infective complications. Men, who felt prepared, reported that **clinical staff had not only provided the information leaflet but also talked through the procedure and gave opportunities to ask questions and clarify misunderstandings**. Men in this study suggested that optimum information provision included face-to-face discussion with a specialist nurse or clinician before TRUS-Bx.	
Chiu et al., 2016 Taiwan	Health education and telephone counselling	CRC	RCT	102 participants Female 51.0% Male 49% Mean age: 57 years- ED 60.49 years - UC	4 week program (3 sessions): (1) F2F Education (2) telephone follow-up (3) telephone counselling	Modified Colorectal Cancer Screening Knowledge Survey (CCSKS-m) Colorectal Cancer Screening Attitudes Survey (4 item) Functional Assessment of Cancer Therapy Colorectal (FACT-C) Impact of Event Scale (IES) State Anxiety Inventory	Knowledge about CRC, attitudes towards CRC screening, symptoms, psychological impact, and anxiety	The health education and telephone counselling program guided by a standardized educational manual helps to reduce the emotional distress of patients with positive CRC screening results who are awaiting colonoscopy. The health education program resulted in a **significant difference in knowledge** about CRC and the psychological impact of a positive screening result between the groups, but the differences of each outcome variable were not statistically significant within a group. The findings suggest that health education provides effective knowledge promotion for patients with positive CRC screening result and **telephone counselling helped lessen the psychological impact.**	100%

Study characteristics

The review includes three papers. The characteristics of included studies are shown in Table 2. In total, 216 participants participated in the included studies. Two studies included only male participants and focused on testing for prostate cancer (Wade et al., 2015; Zeliadt et al., 2013). The third study included both male and female participants and focused on colorectal cancer testing (Chiu et al., 2016). The ethnicity of participants in the two prostate studies were mostly Caucasian (Wade et al., 2015; Zeliadt et al., 2013) and one study did not collect participant ethnicity data (Chiu et al., 2016). The average age of participants across the studies is 61.7 years. Mean of ages ranged from 58.7 - 63.6 years.

Types of interventions

A total of n=154 men received an intervention (see Table 3 for details of the interventions) and n=62 were allocated to usual care. Of the intervention participants: 85 men received an informational leaflet and consultation (Wade et al., 2015); 18 men were given an educational pack including an information leaflet and a decision aid (Zeliadt et al., 2013); and 25 men received an education manual and counselling by a healthcare professional (Chiu et al., 2016). The duration of the education manual and counselling intervention was four weeks long (Chiu et al., 2016), the two other studies did not specify the duration period (Wade et al., 2015; Zeliadt et al., 2013).

Types of studies

All studies were published between 2013 and 2016. Two studies were classified as self-administered interventions (Wade et al., 2015; Zeliadt et al., 2013) and one semi-guided intervention (Chiu et al., 2016). In all of the studies the information element of the intervention was given in a written hard copy format. Participants were given the opportunity to ask questions and gain clarity on the information from a healthcare professional in two of the studies (Chiu et al., 2016; Wade et al., 2015).

Table 3 – Intervention details and components

Study	Specific components of intervention
Zeliadt et al., 2013	• Printed version of Decision Aid • Letter • 12-page booklet on biopsy procedure (explaining concepts such as terminology Gleason score)
Chiu et al., 2016	Total of 3 sessions made up of: • Session 1 – face to face education session with manual (30 minutes in duration) • Session 2 – telephone counselling at weeks 2 and weeks 4 after first visit (10-15 mins in duration, average 12.53 mins) • Session 3 – weekly phone calls after first outpatients appointment
Wade et al., 2015	• Biopsy patient information leaflet • Face-to-face clinical consultation (CNS or clinician)

Types of outcome measures

The study by Zeliadt and colleagues (2013) used semi-structured interviews and quantitative measures including: Stewarts Interpersonal Processes of Care Instrument; Control Preferences Scale; Decision Conflict Scale; Assessment of Patients Experience of Cancer Care; and Memorial Anxiety Prostate Cancer scale to extract data. The study by Wade et al. (2015) was the only study to use in-depth semi-structured qualitative interviews and no other measures. Data was extracted from the Chiu et al study (2016) using the Modified Colorectal Cancer Screening Knowledge Survey (CCSKS-m), Colorectal Cancer Screening Attitudes Survey, Functional Assessment of Cancer Therapy Colorectal (FACT-C), Impact of Event Scale (IES) and State Anxiety Inventory.

Table 4 illustrated the risk of bias assessment for each individual study using the methodological rigour tool developed by Hawker and colleagues (2002).

Table 4. Risk of bias with studies using the assessment of methodological rigour tool

	Study 1 Zeliadt et al., 2013	**Study 2 Wade el al., 2015**	**Study 3 Chiu et al., 2016**
Abstract and title	Good structured abstract with full information and clear title	Good structured abstract with full information and clear title	Good structured abstract with full information and clear title
Introduction and aims	Fair Some background and objective given	Good Full but concise background to study highlighting gaps in knowledge. Clear statement of aim	Good Full but concise background to study highlighting gaps in knowledge. Clear statement of aim
Methods and date	Good Method appropriate full clear details given	Good Method is appropriate full clear details given	Good Method is appropriate clear details given
Sampling	Good full details given	Good Full details given	Good Full details given
Data analysis	Good clear description and details given	Good Clear description and details given	Good Clear description and details given
Ethics and bias	Very Poor No mention of issues	Fair Lip service was paid	Fair Lip service was paid
Findings/ results	Fair Findings mentioned but more explanation could be given. Data presented relate directly to results.	Good Sufficient data are presented to support findings.	Good Sufficient data are presented to support findings.
Transferability/ generalisability	Fair Some context and setting described	Good Context and setting of the study is described sufficiently to allow comparison	Good Context and setting of the study is described sufficiently to allow comparison
Implications and usefulness	Good Contributes something new in terms of understanding/insight or perspective	Good Contributes something new and/or different in terms of understanding/insight or perspective	Good Contributes something new and/or different in terms of understanding/insight or perspective

Synthesis of results

Findings and considerations

This systematic review details three papers for inclusion. This synthesis of intervention studies included one mixed methods study, an RCT study and a qualitative study (Chiu et al., 2016; Wade et al., 2015; Zeliadt et al., 2013). The trials originated from USA (Zeliadt et al., 2013), United Kingdom (Wade et al., 2015) and Taiwan (Chiu et al., 2016). Altogether, these trials included a total of 216 participants. The sample sizes in the included studies varied: the smallest study had 29 participants, while the largest study included 102 participants. The mean sample size was 72 participants. Where a control group was included the studies used ‘usual care’ (UC) as the comparison to evaluate the effectiveness of interventions.

Positive outcomes were reported across all three of the studies. Special reference was given to a: better quality of life and reduction in anxiety while waiting (Zeliadt et al., 2013); gaining clarity and feeling more prepared (Wade et al., 2015); better informed about risks and side effects (Zeliadt et al., 2013); reduction in emotional distress and psychological impact and increase in knowledge about cancer (Chiu et al., 2016).

Two of the studies used an educational intervention with information provision as the main intervention (see Table 3). One of the two also included a decision aid to educate men about the options and help to manage their expectations around the process and procedures (including options for the future). The third study used a combined approach of educational information and counselling (refer to Table 3 for further details).

The outcomes reported across the studies varied. Most frequently reported primary and/or secondary outcomes are knowledge of tumour site information. Other reported outcomes are: perceived quality of life, anxiety and depression. Overall, there is substantial variety across the studies, including variations in the populations, the design and delivery of the interventions, and a wide range of outcome measures being reported. Furthermore, the scales used to measure the variety of outcomes over a range of time points (from 31 to 138 days following intervention) differ substantially, rendering most results across studies incomparable.

Across all three studies, one study gave no data on retention, completion, or attrition explicitly (Wade et al., 2015). Of the remaining two studies that reported completion and attrition, one study reported good completion (7% attrition) (Chiu et al., 2016) and the other reported low completion (without specific figures) (Zeliadt et al., 2013).

Table 5. Outcomes and summary findings

		Intervention				Usual Care		
Study	**Measure**	**Pre-test**	**Post-test**	**P value**		**Pre-test**	**Post- test**	**P value**
Chiu et al., 2016	Knowledge about CRC	15.10	20.98	0.000*		14.65	15.65	0.115*
	Attitudes towards cancer screening	10.90	11.06	0.706*		10.18	10.33	0.679*
	Symptom (FACT-C)	18.61	18.57	0.957*		18.65	19.12	0.385*
	Psychological Impact	20.18	18.10	0.046*		19.37	19.12	0.876*
	State anxiety	48.00	46.86	0.230*		45.84	45.44	0.716*
		Pre-test				**Post-test**		
		Intervention	**Usual Care**	**P Value**		**Intervention**	**Usual Care**	**P Value**
						ED group		
Zeliadt et al., 2013	Anxiety	41.2	51.7	0.13		46.9	51.5	0.64
	Depressive symptoms	7.2	9	0.52		9.6	10.1	0.93
	QOL	48.5	76.4	<0.01		83.6**	75.0**	0.13**

* Mixed gender group results
**Indicates scores for those in the ED group who went on to receive a negative biopsy

Synthesis of quantitative findings

The evidence on effectiveness is limited. A meta-analysis was not possible due to the included studies equating to just one RCT, with a lack of participant homogeneity as explicit outcomes were not separated for male participants in all of the studies (Chiu et al., 2016) or only for specific groups of participants (Zeliadt et al., 2013). Therefore, due to incomplete datasets, the use of Cohen’s d and CI’s was not possible and it was difficult to measure any significant effects to make a definitive statement about which interventions show smaller or larger effects. However, the quantitative analysis summarizes the impact of self-management support interventions on the commoner outcomes such as anxiety, and identifies the support components employed, mapped to the PRISMS taxonomy (Pearce et al., 2015). The evidence of effectiveness of interventions for the commoner components included: information about cancer testing, its management; information about available resources; and easy access to advice or support when needed (see Table 7).

Impact of self-management support interventions on Anxiety

Although not statistically significant, the intervention groups anxiety scores (Chiu et al., 2016; Zeliadt et al., 2013) decreased from pre-test to post-test (refer to Table 5). In Zeliadt et al.'s (2013) trial, anxiety scores were similar for both groups while awaiting the biopsy procedure, with anxiety scores trending lower in the intervention group: 41.2 on a prostate-specific anxiety instrument, compared to 51.7 in the UC group (p = 0.13). However, in the colorectal study (Chiu et al., 2016), anxiety dropped in both the intervention and usual care groups from pre-test to post-test (Chiu et al., 2016).

Table 6 – Summary of the characteristics and key findings from the quantitative reviews

Review, RCTs, participants, duration	**Review focus: target group; Setting; comparator**	**Components of the interventions mapped to the PRISMS taxonomy (Pearce et al 2015)**	**Methods of analysis: Effectiveness on anxiety**	**Comments of authors/ reviewers**
Zeliadt et al., 2013 n = 29 Men. Duration: N/R	Health education for men with raised PSA waiting for a prostate biopsy Comparator: UC	A1. Education (individual) A2. Useful URLs	Anxiety score of diagnosed men compared with UC 46.9 (ED) v 51.5 (UC) P = 0.64	P values should be interpreted with caution as this study was not powered to test specific hypotheses about the intervention.
Wade et al., 2015, n = 85 Men Duration: N/R	Health education for men with raised PSA waiting for a prostate biopsy Comparator: UC	A1. Information about biopsy (individual) A8. Phone nurse	Narrative synthesis – men's anxiety rose when symptoms deviated from the information provided in the intervention	Time lag between intervention and interview may have affected recall.
Chiu et al., 2016 n = 102 participants (50 men) Duration: 4 weeks	Health education and telephone counselling Comparator UC	A1. Education (individual) A2. Available resources regarding screening A8. Face to face consultation and phone access to nurses A12.Telephone counselling A14. Information on cancer prevention	Anxiety score of diagnosed men compared with UC Pre-intervention: 48.00 v post intervention 46.86 P = 0.230 Pre-UC: 45.84 v post UC 45.44 P = 0.716	Symptoms may have varied between subjects (asymptomatic and symptomatic)

Components of self-management support

Information about cancer testing and its management (A1) was a substantial component of self-management support in all three interventions. Table 7 shows the interventions described, mapped to the components of the Practical Systematic Review of Self-Management Support for long-term conditions (PRISMS) taxonomy (Pearce et al., 2015).

Two of the studies used an educational intervention with information provision as the main intervention (see Table 3) (Wade et al., 2015; Zeliadt et al., 2013) and a decision aid to educate men about the options and help to manage their expectations around the process and procedures (including options for the future) (Zeliadt et al., 2013). Two of the interventions also featured information about available resources (Chiu et al., 2016; Zeliadt et al., 2013) (A2). Although the content, and mode of delivery, varied across the interventions, the interventions were introduced or facilitated by nurses. Information and education had some effectiveness in building knowledge. However, outcomes could be improved when combined with easy access to advice or support when needed (A8) (via a consultation with a nurse) (Chiu et al., 2016; Wade et al., 2015) and training/ rehearsal for psychological strategies, namely counselling (A12) and lifestyle advice (A14) (Chiu et al., 2016).

Table 7 - Mapping components to PRISMS Taxonomy

	Chiu et al., 2016	Wade et al., 2015	Zeliadt et al., 2013	Total across studies
A1. Information about condition and /or its management	✓	✓	✓	**3**
A2. Information about available resources	✓		✓	**2**
A3. Provision of/agreement on specific clinical action plans and/or rescue medication				**0**
A4. Regular clinical review				**0**
A5. Monitoring of condition with feedback				**0**
A6. Practical support with adherence (medication or behavioural)				**0**
A7. Provision of equipment				**0**
A8. Provision of easy access to advice or support when needed	✓	✓		**2**
A9. Training/rehearsal to communicate with health care professionals				**0**
A10. Training/ rehearsal for everyday activities				**0**
A11. Training/ rehearsal for practical self-management activities				**0**
A12. Training/ rehearsal for psychological strategies	✓			**1**
A13. Social support				**0**
A14. Lifestyle advice and support	✓			**1**
Total number of components	**5**	**2**	**2**	

Synthesis of qualitative findings

Men waiting for a prostate biopsy procedure welcomed information, and education, about the process, or future potential treatment options (in the form of a leaflet/ educational pack) (Wade et al., 2015; Zeliadt et al., 2013). Men identified the pre-biopsy time as an ideal opportunity for prepare themselves. The men, in the intervention group, who went on to be diagnosed with cancer described benefits such as knowing the risks and advantages of all available options and which side effects mattered most to them (Zeliadt et al., 2013). Men reported a rise in anxiety when their experiences deviated from their expected experiences based on the information provided, and responded by making contact with their HCPs for reassurance, receiving reassurance rather than active treatment (Wade et al., 2015). Men suggested that pre-biopsy information should accurately reflect symptoms to help men manage known symptoms of biopsy and reduce anxiety (Wade et al., 2015). Value was placed on the opportunity to have easy access, or support, to a healthcare professional when needed. Across the studies, the concerns and misconceptions were individual and unanticipated. Information provision is important in enabling men to understand the difference between major and minor complications relating to the biopsy procedure to avoid unnecessary consultations and encourage men experiencing post-biopsy infection to seek healthcare support (Wade et al., 2015). Across the studies, the authors have suggested that appropriate accurate information and education can help to manage men's expectations and provides potential to reduce anxiety, facilitate rapid consultation and avoid unnecessary consultations (Wade et al., 2015; Zeliadt et al., 2013).

Mixed methods narrative synthesis

Table 8 uses the Practical Systematic Review of Self-Management Support for long-term conditions (PRISMS) taxonomy (Pearce et al., 2015) to map insights from the qualitative synthesis and components of the interventions reported in the quantitative studies. All of the men across the studies had undergone at least one cancer test, such as a Prostate specific antigen (PSA) test, Faecal occult blood test, or a Digital Rectal Examination (DRE) that had raised suspicion of cancer. They were waiting for the next test (a prostate biopsy or colonoscopy) to be able to determine a definitive cancer diagnostic outcome.

Table 8 – Qualitative findings and components of the quantitative interventions mapped to the PRISMS Taxonomy

PRISMS Taxonomy	Qualitative Findings	Quantitative
A1. Information about condition and /or its management	Information had a key role in determining how men experienced biopsy, how well prepared they were and potentially had more influence than the severity of their symptoms. Information provision is important in enabling men to understand the difference between minor and serious complications relating to the biopsy procedure to avoid unnecessary consultations and encourage men experiencing post-biopsy infection to seek healthcare support (Wade et al., 2015). Men receiving information who went on to be diagnosed with cancer reported the benefit of knowing the risks and advantages of all available options and knowing which side effects mattered most to them (Zeliadt et al., 2013).	Three studies included information about the cancer early detection period and treatment (Chiu et al., 2016; Wade et al., 2015; Zeliadt et al., 2013).
A2. Information about available resources		Two studies included information on where to find out more information such as useful URLs (Chiu et al., 2016; Zeliadt et al., 2013).
A8. Provision of easy access to advice or support when needed	Men, who felt prepared, reported that clinical staff had not only provided the information leaflet but also talked through the procedure and gave opportunities to ask questions and clarify misunderstandings (Wade et al., 2015). Men responded to anxiety by contacting health professionals for reassurance and most received reassurance rather than active treatment. (Wade et al., 2015).	Two studies provided easy access to nurses for advice and support (Chiu et al., 2016; Wade et al., 2015).
A12. Training/ rehearsal for psychological strategies		One study described psychological support (Chiu et al., 2016).
A14. Lifestyle advice and support		Lifestyle support was included in 1 intervention (Chiu et al., 2016).

There were two main outcome themes identified from across the three studies in this review (Table 9). The first related to the finding that men's experiences, and quality of life, during the cancer early detection period is related to the perceived expectations and preparedness of men. The second theme related to the finding that men's experience, and outcomes, related to the actions they took to manage and cope whilst in transition towards facing the threat of a cancer diagnosis.

Theme 1: Preparedness and great expectations

Men’s experiences, and quality of life, during the cancer early detection period is related to the perceived expectations that men have. Post-test scores were significantly higher than pre-test scores in knowledge about the condition (20.98 v 15.10) and improvements in psychological impact (18.10 v 20.18). Analysis of co-variance revealed that a combined approach of health education and telephone counselling program (Chiu et al., 2016) had a significant main effect on cancer knowledge. Men who went on to receive a positive screening result (either a cancer or pre-cancer diagnosis, such as polyps) reported better outcomes in the intervention group compared with the usual care group. Men reported being better informed about the risks and side effects of each option compared to men diagnosed with cancer in the UC group (p = 0.07) (Zeliadt et al., 2013) and a significant difference in the psychological impact (18.10 v 20.18) (Chiu et al., 2016). Findings revealed that information provision played a key role in determining men’s experiences of having the diagnostic test and how well prepared they were had an influence on their experience and the period afterwards (Chiu et al., 2016; Wade et al., 2015; Zeliadt et al., 2013). Generally, the information component - within the interventions - supported the management of participants expectations, of both the diagnostic process and in preparation for a cancer diagnosis (Chiu et al., 2016; Wade et al., 2015; Zeliadt et al., 2013). This correlation impacted on the range of outcomes including: increased knowledge (Chiu et al., 2016), anxiety and quality of life levels whilst awaiting diagnostic confirmation (Wade et al., 2015; Zeliadt et al., 2013). Men in the intervention group reported a better quality of life (83.6 v 75.0) (Zeliadt et al., 2013) and being more informed of risks and side effects (Zeliadt et al., 2013) with a significant difference in knowledge compared with the usual care group (20.85 v 15.78 p= 0.001) (Chiu et al., 2016).

Anxiety increased when their experience or symptoms deviated from what they expected (based on the information they had been given), resulting in the need for reassurance from healthcare professionals to ascertain the normality of their experience and to manage their concerns (Wade et al., 2015; Zeliadt et al., 2013). Participants highlighted how the intervention needed to reflect fully the range of experiences that they could expect (Wade et al., 2015; Zeliadt et al., 2013) to prepare men. In terms of levels of preparedness those men who felt unprepared experienced distress, due to the disparity between what they had expected and what they experienced, not because of the pain (Wade et al., 2015; Zeliadt et al., 2013).

Men who reported feeling unprepared had experienced symptoms as a result of the diagnostic test (Zeliadt et al., 2013). Interestingly, men in the intervention group, who received a negative biopsy result, saw a drop in their symptoms (prostate cancer anxiety and depression) between baseline and follow-up. The usual care group, with a negative biopsy, had higher prostate worry and depressive symptoms at follow-up than at baseline. ED group with negative biopsy had a decline in prostate cancer anxiety and depressive symptoms between baseline and follow-up. The overall QOL score remained higher for ED group compared with UC group (83.6 v 75.0, p = 0.13) (Zeliadt et al., 2013).

Theme 2: Coping in transition

Men's experiences, and outcomes, during the cancer early detection period are related to the coping strategies they used whilst in transition towards facing the threat of a cancer diagnosis. Findings revealed that failure to prepare men adequately resulted in raised anxiety and additional consultation with their healthcare professional team (Wade et al., 2015; Zeliadt et al., 2013). The impact of the unanticipated experience was to facilitate coping through seeking advice and reassurance. Those men who felt prepared reported that the information and contact with the healthcare professional enabled coping, giving them opportunity to ask bespoke questions that enabled them to talk through their concerns and manage their anxiety (Wade et al., 2015; Zeliadt et al., 2013). A small proportion of men coped with the period using avoidance strategies, not wanting to think about treatment options until after they knew their biopsy results (Zeliadt et al., 2013). In contrast, Chiu and colleagues (2016) found that a suspected cancer increased motivation for learning.

The consensus of these studies is that interventions designed to support men during the cancer early detection period are well received, do not increase anxiety and can provide benefits for users. However, caution must be given to this synthesis due to the small sample sizes, limited data for comparison and small number of studies included.

Table 9 – Mixed methods synthesis of interventions effectiveness, and experiences of men

Theme	Main findings	References
Preparedness and great expectations	• ED anxiety scores lower 41.2 on a prostate-specific anxiety instrument compared to 51.7 in the UC group (p=0.13). • **Better overall quality of life** while awaiting biopsy compared to the UC group (76.4 vs. 48.5, p=0.01). • Those diagnosed in ED group **better informed about the risks and side** effects of each option compared to men diagnosed with cancer in the UC group (p=0.07). Having information about possible treatment options **reduced their anxiety**. • UC group with a negative biopsy had higher prostate worry and depressive symptoms at follow-up than at baseline. ED group with negative biopsy had a decline in prostate cancer anxiety and depressive symptoms between baseline and follow up. The overall QOL score remained higher for ED group compared with UC group (83.6 v 75.0, p = 0.13)	Zeliadt et al. (2013)
	• Key role in determining how men experienced biopsy, how well prepared they were and potentially had more influence than the severity of their symptoms. • Men, who felt prepared, reported that **clinical staff had not only provided the information leaflet but also talked through the procedure and gave opportunities to ask questions and clarify misunderstandings**	Wade et al. (2015)
	• The health education program resulted in a **significant difference in knowledge** about CRC and the psychological impact of a positive screening result between the groups, but the differences of each outcome variable were not statistically significant within a group. • The findings suggest that health education provides effective knowledge promotion for patients with positive CRC screening result and **telephone counselling helped lessen the psychological impact.**	Chiu et al. (2016)
Coping in transition	• A minority of men reported they did not want to think about treatment options until after they knew their biopsy results. Over 80% ED group reported using the materials and 100% of ED who went on to be diagnosed reported knowing the risks and benefits of options and which side effects mattered most to them.	Zeliadt et al. (2013)
	• Men responded to anxiety by contacting health professionals for reassurance and most received reassurance rather than active treatment.	Wade et al. (2015)
	• Suspected cancer increased motivation for learning	Chiu et al. (2016)

Discussion

This mixed methods systematic review aims to answer the following question:

1) What self-management support interventions are effective for men during the cancer early detection period, and how are they experienced?

The review has included three papers which included interventions providing: educational information and healthcare professional input; an educational pack without additional support and educational information, and; counselling with a healthcare professional. Each study evaluated the effectiveness of the intervention to support men during the cancer early detection period, and each provides interesting insights into the potential outcomes of providing intervention before diagnosis is confirmed. It is challenging to ascertain definite conclusions about outcomes and men's experiences across the papers because of the range of methods used across the studies included in the review. Gaps are highlighted for future consideration and trends from the evidence are presented.

It is difficult to draw definitive conclusions due to the small number, and limited focus, of the studies (on prostate and colorectal cancer). However, these studies indicate some evidence that providing information, education and support (from a healthcare professional) before diagnosis may be received well and does not appear to increase anxiety. The use of multiple sources of information to accrue knowledge is a common finding amongst patients with cancer (Beaver, Bogg, & Luker, 1999; Nagler et al., 2010; Sahay, Gray, & Fitch, 2000). The review indicates that participation in some informational and educational interventions may help to prepare and manage expectations about the processes and procedures during the cancer early detection period and may reduce the anxiety experienced. This result may suggest that it is important that men are provided with relevant information to help them to self-manage during the period, to know when it is appropriate to seek additional support (from sources such as healthcare professionals) and where to go to seek further credible information. Failure to prepare men adequately during the cancer early detection period has the potential to heighten anxiety and cause some men to increase contact with healthcare professionals for further advice (Wade et al., 2015). Recent wider evidence suggests that information provision positively impacts on health and wellbeing outcomes in men (Husson, Mols, & van de Poll-Franse, 2011; Patient Information Forum, 2013).

The need for reassurance about concerns and misconceptions was tentatively highlighted across the studies. The need was generally met by contact with a professional from the healthcare team and most received reassurance rather than active treatment (Chiu et al., 2016; Wade et al, 2015; Zeliadt et al., 2013) and two semi-guided intervention. In line with the need for healthcare professional (HCP) contact, the counselling element of the intervention for those awaiting colorectal colonoscopy was highlighted as reducing the psychological impact of the waiting period (Chiu et al., 2016). However, given the projected rise (from 2.5 to 4 million) of people living with cancer by 2030 (Maddams, Utley, & Møller, 2012) and the limited time and capacity for contact with HCPs, it is plausible to consider whether the needs identified (such as reassurance, challenging misconceptions, asking questions and gaining support) might be assessed for the level of support needed and delivered in another way. Outcomes from the studies may offer some insight into potential solutions for further exploration, but these insights must be considered cautiously, as the limited number of studies (and a lack of similar measurements across the studies) make it challenging to ascertain concrete conclusions of the effectiveness of self-management support interventions for men during the cancer early detection period. One unexpected outcome from Zeliadt and colleagues' study (2013) was the prompt from the intervention to use the internet to learn more and access credible URLs. This correlates with Wiljer et al.'s (2013) findings that those patients in the cancer early detection period gain most of their information from the internet and relational sources. Nagler and colleagues (2010) found that clarification is defined by using both multiple sources for validation, in addition to a greater range of source use (including the use of the internet). Galdas et al.'s (2014) systematic review indicates that the internet provides men with a forum to seek support (whilst overcoming cultural expectations of masculinity) and gain emotional support in a relative anonymous, inhibited way (Suler, 2004). Seeking support and information online offers a reduced sense of isolation which can come with the threat of illness such as cancer (e.g. Pitts, 2004) and particularly for sensitive or taboo subjects (Seale et al., 2010).

All of the interventions included in the review were aimed solely at the individual undergoing testing. Other studies (Baider et al., 2003) have identified cancer as an illness process that becomes a complex family matter and not specifically an isolated individual event. Thus, any process of implementing interventions for men with the threat or diagnosis of cancer might be considered within the context of a unit for mutual support. Future research should explore the potential to offer men, alongside their significant others or family unit, interventions to provide reassurance and support to reduce the impact of the cancer early detection period by combining tailored information, psychological support, and an online platform to provide a forum for discussing concerns through.

In line with the transactional model for stress and coping, the individual's appraisal (and reappraisal) of events, and the coping strategies employed, have an impact upon the individual's experience and outcomes. The informational, educational and support elements of the interventions of each study align as mechanisms to aid problem solving coping within the model. There is a suggestion that a greater emphasis needs to be placed on the experiences of men during the early detection period due to a potential correlation between initial screening experiences and longer-term outcomes and retention for future screening and biopsies (Wade et al., 2015). In addition, this review tentatively indicates that health education interventions can provide effective knowledge promotion for those who go on to receive a confirmed diagnosis of cancer. The review has highlighted the gap in interventions that support emotion-focused coping (a process of either avoiding the stressful situation or cognitively reconstructing the context) involved with the cancer early detection period. For example, components may include introducing the use of distraction or reframing which can enable emotional adaption (Bailey et al., 2004; Mishel et al., 2002; Pascoe & Edvardsson, 2016). This raises further questions as to the extent to which 'emotion-focused coping' is an unmet need for men in the cancer early detection period and what priority it is given.

Evidence from this review highlights that provision of an intervention during the cancer early detection period does no harm, and can engage, prepare and inform men to build knowledge and manage uncertainty (about the next steps) to support the waiting period. It is important to remember that some participants did not want to think about the options until after the biopsy results. This highlights the need for a personalised tailored approach, as not every man may need support during the cancer early detection period.

Implications

The review highlighted limited and insufficient evidence, making it difficult to confidently draw conclusions about what interventions are effective for men during the cancer early detection period, and therefore definitive conclusions cannot be drawn from it. The small number, and limited focus, of the studies (on prostate and colorectal cancer) has highlighted a gap in the literature that exists for future research to focus on and explore the understudied area.

It is suggested that there should be additional longitudinal research undertaken to evaluate whether the effectiveness of interventions, and how they are experienced by men is a reflection of their age, ethnicity and level of familiarity with the cancer early detection period. Future research should investigate differences across all age cohorts, tumour sites and cultures. It could be argued that the low number of studies reflects the lack of information and interest in interventions for men during the cancer early detection period. This mixed methods systematic review suggests that interventions are not widely researched and not popular in clinical practice targeting men across different continents. This limited range of information suggests that future studies are needed.

The information, support and interaction from a Health Care Professional can improve knowledge, attitudes and mood during the cancer early detection period. HCPs should recognise the likely effect that unpleasant experiences can have on decisions about re-testing or treatment further along. This is particularly important for certain men (such as those with prostate cancer who consider active surveillance) will need to undergo regular testing as a treatment option (Wade et al., 2015).

Limitations

This study has several limitations. The review excluded studies that were not published in English, and there might be relevant publications in other languages. In addition, no specific guidelines are designed to report mixed methods systematic review, so the study reported elements using the PRISMA (Moher et al., 2009) guidelines (Appendix 2). Another set of limitations concerns the generalisability of the findings. Two out of the three studies were from developed countries, and the healthcare systems may not be generalisable to other countries. The studies were limited to two tumour sites (prostate and colorectal); and all of the studies were conducted with participants who had already received one initial abnormal cancer test (such as a PSA test, Faecal occult blood test, or a DRE). This discussion needs to also take into consideration the lack of consistency across the studies. It was difficult to identify many other specific and direct benefits of interventions for participants during the cancer early detection period. The range of different scales used across studies to report outcomes presents a challenge to interpretation of results: caution is therefore required when interpreting and generalizing the findings of studies reported here.

This systematic review highlights the limited number of studies published identifying interventions that support men during the cancer early detection period. The lack of studies has limited the possible additional analysis and therefore further analysis such as meta-analysis has not been possible. All articles meeting the inclusion criteria have been included in this review, despite not qualifying as ‘high quality’, due to the limited literature around interventions to support men during the cancer early detection period.

Conclusion

Relatively little is known about the self-management support interventions for men to access during the cancer early detection period, across cancer tumour sites. To date, there has been a lack of understanding about which intervention components are effective and what associated outcomes and experiences men have within this group.

Although it is difficult to ascertain what interventions are effective for men during the cancer early detection period, due to the very limited literature and insufficient evidence, this review has provided some limited evidence from three studies supporting the use of information and education and professional input to improve outcomes for men within the cancer early detection period. Each study has reported some positive outcomes. This review provides some understanding of how interventions are conducted in male populations within the cancer early detection period and the results will contribute to the development of an intervention designed to support men in the period, and has highlighted the gap to guide future research within the area. This review is the first of its kind to identify the interventions that offer support to men, documenting the outcomes and experiences. This adds to the current (limited) research and highlights the need for more empirical research into the identified and prioritised needs of men during this period.

Chapter 3 – A qualitative interview study to identify the needs of men during the cancer early detection period

Introduction

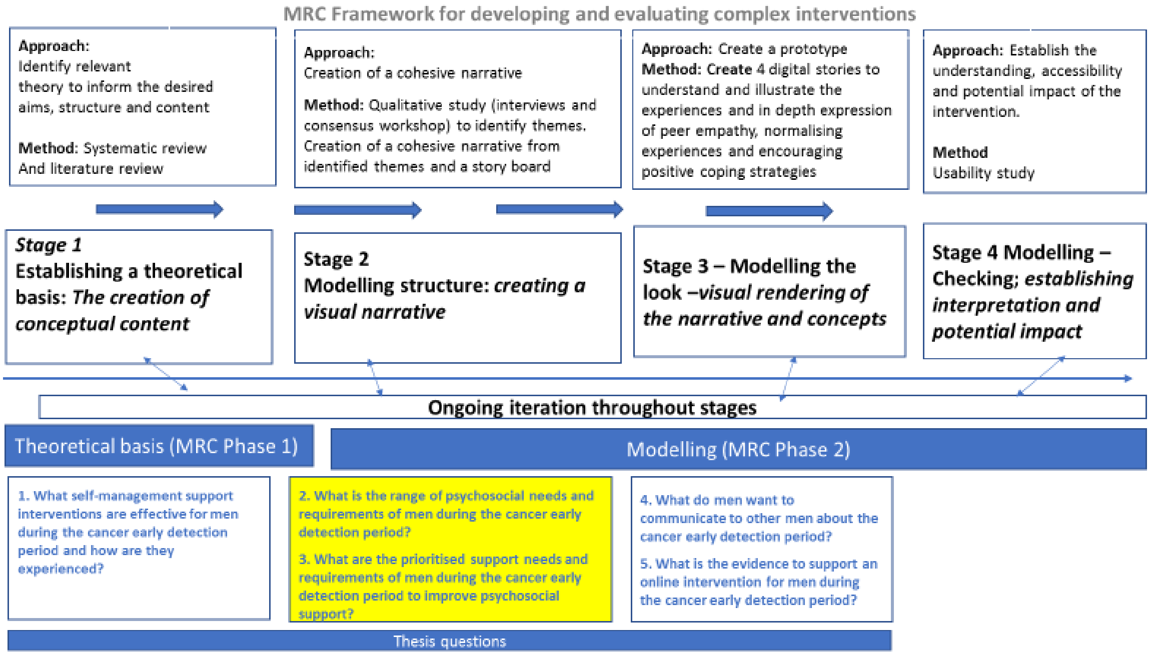
The preceeding chapter provided evidence suggesting the need for some information, social support and emotional support during cancer early detection period (Chiu et al., 2016; Wade et al., 2015; Zeliadt et al., 2013). However, it acknowledged that the focus of the limited studies was on the wider experiences of the cancer early detection period and not on identifying the specific needs of men within the studies (Awsare et al., 2008; Dillard et al., 2017; Medd et al., 2005; Roumier et al., 2004). The limited findings from the chapter highlighted the need for further empirical research to understand and identify men's needs across numerous cancer tumour sites. The need for further empirical research, to understand and identify men's needs, provided the rationale for this current study. Being able to identify, earlier in the cancer pathway, future men who may need more support than others (particularly those at a heightened risk of poor psychosocial health) has the potential to reap benefits. NICE (2015) guidelines highlight the lack of current evidence (particularly qualitative studies) assessing information needs, and key issues in patient experience, in the cancer diagnostic pathway. The guidelines recognise that filling the gap should improve future patient experience (NICE, 2015). In recognition of the lack of current qualitative evidence and need to gain an indepth understanding of men's support needs, a qualitative in depth research method was considered to be optimal. Considering the sensitivity of the topic, as outlined in Chapter 1, a one-to-one interview study conducted over the telephone, would be more conducive given the sensitive topic. The insight gained may have implications for further research on information and brief interventions designed to provide support for men during the cancer early detection period.

The early detection and diagnosis of cancer greatly increases the chances for successful treatment and survival (Cancer Research UK, 2017a, 2017b). There are two major components of the early detection of cancer: education to promote early diagnosis, and screening (World Health Organisation, 2017). The duration of the cancer early detection period varies according to the tumour site being tested, but recently a 28-day faster diagnosis standard has been introduced to ensure that patients find out within 28 days whether, or not, they have cancer (NHS England, 2016a, 2016b). Previous work (Padgett et al., 2001; Yardley, Davis, & Sheldon, 2001) has identified the cancer early detection period as one of mixed emotions, with high levels of stress and anxiety (Halbert et al., 2010; Wiljer et al., 2012, 2013). Growing evidence suggests that the period before the confirmation of cancer diagnostic test results can be more distressing than receiving the diagnosis of cancer (Dale et al., 2005; Fantini-Hauwel et al., 2011; Liao et al., 2008), and potentially affects choices after diagnosis (Denberg et al., 2006; Dillard et al., 2017; Drageset & Lindstrøm, 2005; Widerman, 2004). This period is important, as a proportion of the tested men – such as approximately one third of men undergoing prostate cancer testing – will receive a confirmed diagnosis of cancer (Zeliadt et al., 2013) and have a treatment pathway ahead of them. It could be argued that this has the potential to create a burden for the individual and healthcare resources. Previous studies have routinely identified that anxiety about a cancer diagnosis hinders the processing of information about risks and the range of benefits of different treatments (Denberg et al., 2006; Zeliadt et al., 2006). Therefore, the timing of support and education about the options for treatment may be critical as research on decision making in prostate cancer (Ramsey et al., 2009; Zeliadt et al., 2010) confirms that the majority of patients arrive at a treatment decision rapidly following diagnosis with most men only considering one option. Fear and uncertainty have been cited as reasons by men who decided against active surveillance, opting for treatment instead (Denberg et al., 2006). In colorectal cancer studies, a pre-cancerous diagnosis has been found to have a profound effect on an individual's emotional psychological wellbeing and causing anxiety regarding examination and diagnosis (Denters et al., 2013; Wiljer et al., 2013). Therefore, NICE (2008) recommends that one way to manage the burden is to provide good supportive care for men, to enable them to make informed decisions and support effective coping. Preferably, such care should include self-management, to foster independence (Cockle-Hearne & Faithfull, 2010). However, the available guidance on supportive care and self-management is mainly focused on the post-diagnostic period and is generic to all cancer patients (NCSI, 2013). Studies indicate that identifying the needs of patients enables effective allocation of resources for improving quality of service provision (Bonovski et al., 2000; Gustafson et al., 1993; Gustafson et al., 2003).

In line with the MRC framework, used in Chapter 1 (see Figure 3), a review of the literature, set the context and provided a narrative background to the issues in relation to men and the cancer early detection period. The chapter highlighted that the prevalence of distress was variable across studies (Brindle et al., 2006; Carlsson et al., 2007; Dale et al., 2005, Essink-Bot et al., 1998; Gustafsson et al., 1995; Medd et al., 2005; Wade et al., 2013). Several studies identified that the highest priority needs for men during the cancer early detection period are the need for information, social support and emotional support (Wiljer et al., 2012, 2013). The most prevalent unmet need related to: being signposted for further credible information (and support), and; a lack of emotional support. It identified that supporting men to build on skills provides benefits in terms of managing emotions, such as anxiety, whilst improving wellbeing outcomes (Wiljer et al., 2012, 2013). The wider literature highlighted certain groups of men who may be at higher risk of unmet psychosocial needs due to their circumstances, such as men over 50 years old with a family history of cancer (Dale et al., 2005; Gustafsson et al., 1995; Medd et al., 2005). Therefore, it is recognised that there is a greater need to support certain men who experience distress during the initial cancer early detection period, with the appraisal of their thoughts and feelings. By providing a mechanism to highlight and recognise distress there is opportunity for intervention. One solution, and a way of facilitating this, is by providing an intervention which enables men to reflect on other men's experiences. A peer support function communicating difficult emotions and experiences, within an intervention, offers an opportunity for the acknowledgment of distress, reappraisal and readjustment.

The mixed methods systematic review, outlined in Chapter 2, identified three studies which explored the use of interventions to support men during the period. The studies' intervention types focused on supportive information, educational resources, and a combination of counselling and education (Chiu et al., 2016; Wade et al., 2015; Zeliadt et al., 2013), and they identified several findings. Firstly, providing information, education and support before diagnosis is well received and does not increase anxiety. Secondly, there is research suggesting that participation in informational and educational interventions can help men to prepare and manage expectations about the processes and procedures during the cancer early detection period, and thereby reduce the anxiety experienced. In addition, the review indicates that health education interventions provide effective knowledge for those who go on to receive a diagnosis of cancer, and can engage, prepare and inform men to manage uncertainty. The review confirmed that no evidence-based, online peer support, self-management, intervention currently exists for men to access during the cancer early detection period. These findings provide evidence to suggest that an intervention introduced within the period is likely to be received well, is unlikely to raise anxiety, and could help men to prepare effectively, especially those who go on to receive a confirmed diagnosis. It highlights a gap in current provision and provides an opportunity for an intervention to address the unmet needs of men during the period.

Figure 7. MRC Framework Phase 2 – Stage 2



Therefore, in line with the MRC Framework for developing and evaluation complex interventions (refer to Figure 7) (Craig et al., 2008), the purpose of this chapter is to understand and extend current knowledge of the range of needs that are important to men during the cancer early detection period, to enable the creation of a 'cohesive narrative' around unmet needs (Phase 2, Stage 2) (Craig et al., 2008). The overall methodological approach of critical realism recognises that knowledge is gained from individuals' objective reality, through their subjective lens, and interpreted by the researcher. Throughout the study, from the questions to the procedure, consideration was given to providing an opportunity to explore with participants their interpretation and understanding, thus acknowledging the influences that can impact on it (Bhaskar, 2010; Maxwell & Mittapalli, 2010; Scott, 2007). Therefore, this chapter explores the thoughts and emotions of men in relation to their experiences of the period, to evidence and uncover issues, needs and coping strategies used. The findings of this study will be used to identify and prioritise the range of needs and issues men experience during the cancer early detection period.

Aim and research question

The aim of the study is to understand the identified needs of men who have been through testing for cancer.

Research question: What is the range of psychosocial needs and requirements of men during the cancer early detection period?

Method

Study design

In accordance with the aim of this study, and critical realist approach to the thesis, it was necessary to select a study design that would enable the objective reality, through the subjective lens of participants, to be captured in the knowledge generation and interpretation. It was important to gain insight, whilst ensuring the potential need for anonymity, found to be important in engaging men in research within cancer care (Beatty, Koczwara, & Wade, 2011; Duffecy et al., 2013; Leykin et al., 2012; van den Berg et al., 2013). Qualitative research enables a greater investigation of the impact of context (Braun & Clarke, 2013). Therefore, the format of the interview study was selected in order to cultivate engagement with participants individually, which is more conducive to the discussion of sensitive topics than other formats, such as focus groups (Gill et al., 2008). Telephone interviews were chosen as they extend access to participants, due to the synchronous communication of place, compared to face-to-face interviews (Opdenakker, 2006). This enables access to participants who may be deemed harder to reach or work with on a face-to-face basis. In addition, studies indicate that for sensitive matters, interviews by telephone might be more appropriate than ones in person (Greenfield, Midanik, & Rogers, 2000; Sturges and Hanrahan, 2004; Trier-Bieniek, 2012). The use of open-ended questions, based on the aims of the study, were considered ideal to provide participant-led investigation of the topics, achieving a balance between breadth and depth (Britten, 1995). As participants were recruited directly via support groups and community groups, full health research ethics committee approval was not required (as recruitment was not via healthcare professionals or a healthcare provider). To meet Coventry University guidelines for studies undertaken by students, an ethics application was submitted, and approval granted by the Health and Life Sciences (HLS) Ethical Committee ID: 50660.

Participants

Male participants were recruited during the period of the study between May and June 2017, through several approaches:

- An email and poster (Appendix 7) about the study was distributed across the Midlands, via the community and voluntary sector networks and service development team at Macmillan Cancer Support
- Information about the study was distributed via a poster at national Macmillan events (including, for example, the UK Volunteers Conference)
- The method of snowballing was used (as participants were asked at the end of the interview whether they knew of anyone else who may want to be involved)

Those interested were invited to contact the researcher to register their interest in being involved by responding directly by email or a phone call. Once participants registered an interest they received an information sheet (Appendix 8) and consent form (Appendix 9) to sign and to send back in a self-addressed envelope. A mutually agreeable date and time for the telephone interview was arranged. Participants were asked for the following demographic information before the interview: age, relationship status, result of cancer test (benign or cancer diagnosis), and date of diagnosis. Participants were given a participant number for the purposes of anonymity (and pseudonyms were given to the names of anyone referred to during the interviews such as healthcare professionals or family members). Inclusion criteria included:

- men (aged ≥18 years)
- been through the cancer early detection period (the time point from either attending asymptomatic screening or a diagnostic test, up to when the test results are confirmed for any cancer type)
- either received a cancer diagnosis or benign result
- resident in the United Kingdom
- speak English

Procedure

Upon receiving written consent, a mutual date and time for the telephone interview was agreed with the participants who had registered an interest, to ensure that retention was maximised. The interview schedule focused on the needs of men during the early detention period and was developed through an iterative process, born out of the findings from Chapters 1 and 2, and informed by the Transactional model of stress and coping. With the aim to understand the identified needs of men who had been through testing for cancer, it was important to ensure information was captured on the appraisal, coping and outcome of the period. The schedule initially included directive, topical questions to elicit information about the participant's experience of the waiting period. For example, the opening question asked: *Can you tell me about the waiting period between having screening (or a test) and then receiving the results of the test?* The interview schedule also included broader questions to elicit information about their feelings, thoughts and perceptions during the period: *How did you feel during the time leading up to getting your test results?* The interview schedule was piloted with two participants first and very slight revisions were made to the questions to make the language plainer and easier to understand. The schedule was developed with the purpose to contribute detail on specific areas for exploration connected to the overall aims of the qualitative study, attempting to achieve both a depth and breadth of answers to each question.The schedule contained two parts: a) a format enabling participants to share their experience of the cancer early detection period, in their own words, and; b) questions developed to understand the specific needs and coping strategies of the participants (See Appendix 10 for interview questions). To increase the comfort of participants, open-ended questions were used, and the researcher engaged with participants in a friendly, empathic, sensitive manner during the interviews (Elmir et al., 2011). Participants were encouraged to stop the interview at any time, if needed, and to ask questions of clarification. Participants were made aware of the Macmillan Cancer Support helpline phone number and were reminded that they could withdraw informed consent. Interviews were recorded on a Dictaphone and transcribed verbatim.

Analysis

The aim of the study was to identify a list of support needs from participants to inform a subsequent NGT study (to lead to the prioritisation of needs). Therefore, in order to identify a broad list from participants, the process of thematic analysis was selected as the most appropriate method to enable the generation of support needs (Braun & Clarke, 2006). To be able to inform the subsequent NGT study, the analysis followed the six-phase process by critical reflection (see Appendix 6) (Braun & Clarke, 2006). The inductive data-driven approach was considered to be beneficial (as outlined in Phase 2 and Phase 3 of the process) as it allowed for the identification of unexpected themes within the data (Braun & Clarke, 2006).

The interview transcripts were individually read twice and examined in depth and notes were made. Initial coding was applied with the purpose of being open to many interpretations. The codes applied described a participant's experience or thoughts and where possible links were made between identified needs and coping mechanisms. Development included the constant review of the incorporated areas of interest from the interview schedule, which led to new, emerging codes. The codes were reviewed after each interview and revised to include the new emerging codes. Once coding was complete, focus was given to identifying the themes. This was an iterative process which enabled the development and emergent of themes, the highest level of coding. Constant comparison and review of the themes enabled progression to focus on establishing the sub-categories of themes which became evident, and lower levels of coding were highlighted (Braun & Clark, 2006). The codes and themes were organised using NVivo 11 software. In acknowledgement of subjectivity within qualitative research, several steps were taken to ensure that the risk of bias during the analysis of the data was minimised. This included peer debriefing, whereby the supervisory team were involved at several stages of the analysis including: independently examining the interview transcripts alongside the codes, and providing feedback at the initial stages of generating the codes (Phase 2). Further accuracy and consistency checking was done when reviewing the themes (Stage 4) across all transcripts. Coded transcripts were examined and revision of codes and themes was agreed during discussions. Disagreements were identified and the reasons were discussed in detail. The discussion of disagreements supported a reflective process which supported development and revision. Following the coding, and application to a theme, a table was created to list the themes.

Irrelevant text has been omitted from the quotes and replaced with an ellipsis ('[…]'). Square brackets are used to clarify topics of discussion. Participants' codes (P) are indicated at the end of the quote to clarify who it relates to.

Findings

Characteristics of the sample

Twenty-five men were successfully recruited, with a wide range of ages from 40-85 years, and from across the UK, with the majority from the Midlands region. Of the cohort, three men were single, two divorced, one widowed, one separated, one cohabitating and the remaining seventeen were married. The majority were white British (22 participants), with the exception of one Black African participant and two White Irish participants. Three men described their sexual orientation as gay, and the rest of the sample identified as heterosexual. Twenty-one of the men reported that they had received a diagnosis of cancer, and four had not. Those who had been through cancer testing within the last five years accounted for twenty-one men, and four had been through testing more than five years before interview. Those men who went on to receive a diagnosis had a variety of cancer tumour sites, with the most common being prostate cancer (see Table 10 for full details):

Table 10 - Characteristics of men interviewed with participant identification

		Study Participants
Age at interview	Mean	65 years
	Range	40 - 85 years
Relationship Status	Single/divorced/separated	6
	Married	17
	Widowed	1
	Cohabiting	1
Sexual orientation	Heterosexual	22
	Gay	3
Cancer tumour site	Prostate	10
	Bladder	5
	Testicular	2
	Head and neck	2
	Colorectal	1
	Breast	1
	Tongue	1
	Non Hodgkins Lymphoma	1
	Kidney	1
	Saliva Gland	1
Time since testing	Mean	41 months
	Range	3 - 206 months
Cancer diagnosis	Yes	21
	No	4

Key themes

Twenty-five themes emerged during the analysis of data and are illustrated below in Table 11.

Table 11 – Themes related to the needs of men during the cancer early detection period

Theme	Identified needs
1	Accessibility and acceptability of social support network
2	The importance of a supportive individual
3	The value of peer support (and the lived experiences of others who had experience of cancer)
4	Gaining knowledge through credible information sources
5	Gaining control through increased knowledge
6	Preparatory information seeking (supports the next stage)
7	Internet use for knowledge and information gathering
8	Importance of individuality and person-centred support
9	Dealing with anxiety, shock and disbelief
10	Perceived control to plan and prepare
11	Ability to plan and prepare for next steps and the future (much wider than health)
12	Having an outlet for releasing anxiety and worry
13	To have a distraction such as work (paid or voluntary) or meaningful activities
14	To ‘compartmentalise’ the anxiety and deal with it in stages
15	The use of humour to lighten communications
16	Dealing with uncertainty
17	Psychosomatic impact on physical health
18	Confidence and support to self-manage (willing to self-manage but having the confidence to know what is ‘right’)
19	Issues of masculinity, stoicism, cultural expectations
20	To not ‘burden’ others and selective disclosure
21	Gender of Healthcare professionals involved in care
22	Risk perception communicated by healthcare professionals and trusted others
23	Communicating the results of the test
24	Effective, honest and open communication from Healthcare Professionals (upfront and to the point) with compassion
25	The role of HCPs and trusted others in instilling hope and confidence

Theme 1: Accessibility and acceptability of social support network

For many participants, the presence of a good social network made up of friends, family and trusted acquaintances offered them support and reassurance whilst waiting for results:

> *"I didn't particularly look for support but I suspect actually I was getting a lot from friends who'd gone through or were going through the experience. And […] through that, quite a lot about it produces relaxation if you understand whats happening and why its bound to help […]. Well friends who'd had the same experience, one of them was a GP […] he was going through the same experience at the same time. I'd had friends who'd gone through it. They were sources of information"*

How readily accessible the network was viewed to be and how they perceived the acceptability to talk about their experiences was important, and had an impact on how readily they disclosed "*we've got some friends that we've known for forty odd years and I told them 'cause they said 'right what's happened' and I explained..."* (P20). The use of the network included: increased knowledge around expectations of what might happen next; an aided problem-solving approach, and; alleviation of some fears if a cancer diagnosis were to follow. Several men acknowledged the positive impact that the support network had on them. Knowing that they could contact them, when they needed support, was enough support in itself "*phone my best mate, my Sister-in-Law […] and other people in my family that are connected with the Health Service"* (P3). Supporters in their network who: worked in the NHS; were a healthcare professional, or; affiliated with the healthcare sector in some way, were regarded as good sources of support due to the additional knowledge and resources that they brought.

Theme 2: The importance of a supportive individual

Significant value was attached by participants to the support provided by their partners or a trusted other (such as a parent, sibling, daughter or best friend):

> *"until the diagnosis the only person I really spoke to about it was my Dad…it was kind of, Dad I've had these symptoms, I'm going for tests, I don't know what it is, I'm scared, it could be something […] I was facing very quickly the potential that I was gonna die in the not too distant future. That was one of my initial thoughts…chats with my Dad calmed me down." (P21)*

The supportive individuals were cited as a main source of support to: talk to; act as an aide memoir, and; provide emotional and practical support. Participant 25's daughter provided him with emotional support by *"knowing the right things to say and how to make me feel."* Participants who were married, cohabiting or in a partnership acknowledged the positive effect of having an 'accessible supportive individual' that brought emotional benefit and social support to them:

> *"you start to feel really down like you know which is not unusual and then you try to get through the day […] I was lucky my wife was with me, I wasn't on my own"* (P6)
>
> *"my wife is a Midwife. She's always been very, very supportive. She was my one main source of support"* (P13)

They recognised the potential consequences for those who did not have that support:

> *"if you're single and you have no-one around you […] I firmly believe that that could enforce things in another way if your mental well-being is not strong enough […]. It forces you down a route mentally, which I believe has a more negative impact on you, your potential outcome. […] that's what it felt like at the time. Be strong, be strong, be strong otherwise it just gets on top of you."* (P22)

Participants who were single, separated or widowed identified a potential void of support. They acknowledged this as a need, and actively sought out other ways to gain support through trusted health care professionals. Acknowledgment was given to the impact of having a lack of support:

> *"I mean the Psychologist did ask me if I've got anybody I could talk to family wise or friends I could speak openly […] I have got a brother […] And he's ill himself […] I didn't want to worry him anymore. Discussing things like this […] it would have been really nice if I'd have had a partner or a wife that I could consult with and give me real support. Someone I could talk to every day."* (P8)

Theme 3: The value of peer support (and experiences of others)

Many participants, who went on to receive a diagnosis, found support groups beneficial and reported the positive emotional support and reductions in feelings of social isolation from attending. The peer learning opportunity presented by support groups enable information to be taken on board in a safe trusted environment and provide an opportunity to share feelings. One participant talked about the positive impact he experienced following a suicidal point:

> *"I remember waking up in the middle of the night […] thought I'd rather die. […] and remember thinking I really don't care if I don't wake up. That's how you can feel at times. To be frank I did get quite suicidal, I nearly threw myself off the 14th floor. That how low you can go. My personality had changed so much because I'd given up a good job, I was readjusting to a new job, a new me. It was only when I got to the support group and started talking to people and knowing they'd gone through exactly the same experiences as myself, bouts of desperation, and what's the point of all this and that where you really, really do feel support groups understand it."* (P2)

The support offered by groups provides a sense of belonging and a collective shared understanding around experiences with others with a lived experience 'like them'. Participants' experiences of peer support facilitated the sharing of information, ideas and thoughts about their experiences, making them feel less isolated. The mutually beneficial nature of talking and sharing was experienced as *"knowing"* and *"understanding"* (P2). Peer support was identified as an important need, and provided support for men to make sense of their experiences and the transition (between health and potential illness) they were undergoing. Participants recalled reaching out to friends of a similar age, many who were "*going through the same process"* (P4), which made it valuable to *"share notes with them"* (P4). Participants identified the positive effect peer support had in enabling them to adjust to a diagnosis and face the next steps. The chance to talk through with another man who has been through a similar experience, for peer support, was not given as an option by healthcare professionals, and identified as an unmet need. Participants didn't know where to go to access peer support and talk to "*somebody else who'd been through it"* (P18) because *"at the time it seemed like the end of everything"*, and would have been "useful" (P21) to talk to somebody or to attend "*group sessions"* (P21). This unmet need was spending *"a huge amount of time going onto the internet"* (P21).

A range of peer support options were identified as beneficial, from informal one-to-one support (friendship networks, families, work colleagues) to group support (peer led, professional led, face-to-face or online). The importance of reciprocity in each support option was evident "*they can come back with their experiences […] how they felt so you get a lot of information from there"* (P16) whilst also acknowledging the limitations: *"it might not be directly the same […] but it gives you some ideas"* (P16).

Theme 4: Gaining knowledge through credible information sources

Accruing knowledge facilitates a process to gain control at a time when feelings of anxiety and uncertainty are experienced. Gaining insight from credible written information gives a sense of reassurance, being more informed and aware of the potential future. Participants recalled how bespoke literature that was tumour specific was "*very useful"* (P13) with the need for multiple credible sources being important. However, deciding which sources were credible, and which were not, presented a challenge:

> "*It would have been useful just to have or been told that there was somebody I could call up or go and see or group sessions 'cause there is so much information out there that you can access so easily…it would have been nice to have had some information given me so that I knew what was trustworthy if nothing else […] I didn't know what was reliable and what was not reliable at the time."* (P21)

Participants described the difficulty of assessing what 'accurate information' is, as it "*isn't always possible"* (P11) due to the numerous articles on the internet "*that have little to do with real life"* (P11)*,* citing *"I could have found a miracle cure […] at only £55 a go and […] be instantly cured"* (P11) but wanted references of *"where you could find the information you need reliably"* (P18). Participants were aware of the potential risks and consequences of gaining information and knowledge that is not credible, and the cost to them emotionally at a vulnerable time. Participants recalled how some online blogs misled them with "*people talking complete rubbish"* (P21) which impacted on the period leading to believing the "*wrong things"* (P21) and experiencing emotional turmoil which "*will tear you to pieces"* (P21)*.* Participant 15 described feeling "*bombarded with leaflets" and* recalled the *"first port of call is the internet"*, which can either reassure or *"horrifies you depending on what you find".* The ambiguity had a disabling effect which resulted in him not seeking "*outside help".* In addition, being able to talk through the information with a credible source was identified as a source of comfort. He concluded by describing the additional benefit of the credible person also having had a lived experience of cancer and described the benefit of using the cancer information centre at the hospital as the information manager had "*gone through it"* which was valuable and gave benefits "*talking to him."*

Theme 5: Gaining control through increased knowledge

During the cancer early detection period, whilst awaiting the outcome of tests with limited knowledge of prognosis, participants experienced feelings which challenged important aspects of their lives. The uncertainty experienced, described as the "*unknown"* (P1), led to the feeling of being *"not quite in control"*, and waiting for test results meant that *"you can't plan, […] (it's) a challenge".* In response, to gain some control and increase understanding, participants gathered knowledge from a variety of sources:

> *"I was given […] various literature to read. More about the process of having the biopsy's and […] that was the written guidance I had and I looked on the Internet myself and […] also I talked to […] people I knew, […] colleagues, ex-colleagues of a similar age or friends and found a couple of those that had been or were going through the same process […] I'm one of those sort of people that […] like to know the ins and outs of things so it was useful to, […] know where the prostrate was in the body and what it did and what, […] an enlargement meant. And also inbetween having the biopsy and waiting the results if treatment was necessary, what would be done. You know, what type of treatments and […], how […] successful and unsuccessful they were."* (P4)

The credible sources ranged from written information to knowledge gathered from talking with: trusted others; those with a lived experience, and; healthcare professionals. Participant 5 described how talking to his cousin (who was diagnosed with breast cancer) had helped, as she seemed to cope "*well"* with it, whilst acknowledging that perhaps she had put "*too positive a slant on things".* The opportunity to learn from another person's experience had a reassuring impact. Several participants talked about becoming more knowledgeable about the healthcare 'system' and what to expect, with reference to experiencing feeling part of a 'process' or on a 'production line'. However, as their knowledge about the system increased, so did their confidence to take back control, rather than 'allow' the system dictate to them. Participant 6 described his experience of challenging the administrative oncology booking clerk, stating "*I want you (to) make my appointments […] like […] at the Dentist".* He recalled her saying "*we don't do it like that"* and so challenged *"well there's no reason why you can't, is there?"* at which point she agreed. By taking control and questioning the logic, he was able to feel in control of his own calendar and prevent "*sitting at home waiting for a letter to be delivered."*

Theme 6: Preparatory information seeking (supports the next stage)

Appropriate tailored information can act as a buffer and help prepare for a potential diagnosis. However, the amount, level and type of information that is appropriate for each individual will vary. Participants who had received information, talked about how it helped to prepare them and provided a buffer when the diagnosis was delivered. Participants recalled the relief felt at diagnosis when the cancer was not as advanced as feared, describing how reading on the internet had helped to prepare. Participant 5 recalled the statistics and described how he had spent two to three weeks "*wondering how far it got"* and pre-empting what effect it may have:

> *"I know this sounds really strange but I was sort of slightly relieved in some way […] he Nurse had said I think it's a T3B and whatnot and basically I done quite a lot of reading up on the Internet which is a both a good thing and bad thing I think, and I was sort of fairly happy I think for it not be a Stage 4. So to a certain extent […] it was a relief as I'd spent two or three weeks thinking, wondering how far it got and I really, really don't want it to be a 4 because you look at all the stats don't you and the percentages of survival rates, things like that are significant and your quality of life."* (P5)

Participants talked about the importance of having information to hand ready for the most appropriate time of need, as it acted as a reminder. Participant 23 had been under surveillance for several years with fluctuations with his PSA levels and recalled "*I had the books […] I read through them and reminded myself in 2017 what the situation was"* and added the benefit they gave, as after reading them he "*didn't feel the need to get any support."* In addition to the timing of information, the amount and appropriateness made a difference to the experience of the ongoing process. He described feeling "*clear about what was happening"* throughout the process. He recalled the benefit of "*enough information […] with the path that was taken"* and described the positive effect the information had which resulted in him feeling "*content. You can't be happy, you've got cancer, but content"* (P23).

Theme 7: Internet use for knowledge and information gathering

> *"from what I'd been told, from what was on the internet and also You Tube videos of the eventual procedure was going to be so I knew what I was going to get […] I had taken a list of questions that had built up from having different things on the internet."* (P14)

The use of the internet for health-related applications was highlighted as important to participants as it offered an anonymous and time-limitless avenue to obtain information and support. To gather knowledge through direct searches or via social media was an easy option for many and often the first port of call before telling other people. Participant 2 talked about how he turned to the internet to find out more following a consultation and was "convinced" that the following appointment was not just routine, as on *"the notes it says 'suspected SCC' […] I took a copy of that, and obviously when I got home I googled 'SCC' to see what it was"* (P2). Healthcare professionals are aware of the support the internet can give many men. However, acknowledgement was given to the cautionary aspect of reading information out of context and the potential for emotional distress and precipitation of anxiety, creating a feeling of being "*in trouble"* (P22). Researching on the internet was recognised as both a *"wonderful thing"* (P22) but also *"a bad thing"* because it provides statistical information about survival rates and recalled "*the percentages of people who survive Gleason scores of 8"* and "*those numbers aren't high".* Other participants described not looking on the internet as a form of protection as "*there's that much misinformation on there"* (P25) shielding from *"more doubts"* as *"it could be this, or it could be that"* deciding "*ignorance is bliss."*

The relative anonymity offered by the internet reduces inhibition and offers emotional support, based on personal experiences, which participants valued. Availability is irrespective of geographical or physical constraints and has the potential to reduce a sense of isolation which can come from feelings of uncertainty or experiences of waiting. The opportunity for peer support accessed via the internet offers an opportunity to connect with other men in a 'safe space', overcoming overt issues of masculine ideals, such as stoicism. Participant 16 talked about the support he gained from "*Checkemlads.com. […] a UK based charity"*, which provided the opportunity to ask "*the silliest question"* because "*everyone that's on there has suffered testicular cancer"* (P16). The opportunity for participants to share with others who have been through a similar experience offered participants a space to think about the next stage and enabled them to think about *"a lift of questions"* (P14) they wanted to ask during the diagnostic consultation "*built up"* from "*different things on the internet".*

Theme 8: Importance of individuality and person-centred support

Participants identified how their needs and preferences were bespoke to them as individuals and recognised the pressures and challenges of providing person-centred care within the healthcare system and infrastructure:

> *" I felt as if it was scripted. They weren't looking after, I can't say that can I? The NHS do a remarkable job but in this case if they'd looked at the person instead of a statistic it should have been better.[…] make matters improve by looking at the person, the whole person as a whole then it would have been a lot better." (P7)*

Participants valued flexibility within the system as each individual is "*different"* (P2) and *"reacts to […] diagnosis differently"* (P4). Recognition was given to an optimal individual approach being "*treated as a person not just a case"* (P13). There was recognition of the opportunity for healthcare professionals to communicate with "*more openness"* (P13) *as "being open and honest helps you to deal with things a lot better"* (P2). Recognition was given to the personal preferences for coping: "*how I coped with it is not appropriate to everyone else. It was my unique set of circumstances"* (P2).

Participants acknowledged the consequences of when a person-centred approach is compromised, due to time or capacity of the system or healthcare professional, leading to feelings of frustration and disregard. Participants reported experiences being "*scripted"* (P7) and part of a *"production line"* (P18) which subsequently resulted in feeling that they *"weren't looking after […] the whole person"* (P18), which resulted in feeling *"uncaring at the time"* (P21).

The role of the healthcare professional in person-centred decision support was acknowledged as being of particular value. Benefit was gained from the shared dialogue, with healthcare professionals (HCPs), to make informed decisions about the next stages because it is "*no-one else's decision" (*P22) and personal *"choice".* Value was gained from learning from the HCP's experience, and recognition was given to seeking advice by asking questions such as "*what's the best thing to do here? What's the safest thing to do?"* (P22).

Theme 9: Dealing with anxiety, shock and disbelief

> *"it was a shock […] my mind was in turmoil […] I was worried […] It was frightening. […] I had a heart attack. I don't know what bought it on. I don't know whether it was the stress, the worrying I don't know, but I had a heart attack." (P8)*

Feelings of anxiety and distress were common during the waiting period. Participants expressed these in different ways, such as *"going into a darkened room. And shutting the door…"* (P12). Participants described their feelings as *"Wound up, anxious, depressed" (P18)*, *"apprehensive, worried"* (P7) and *"on a downer"* (P7). The apprehension and uncertainty experienced, with reflection of the potential impact, induced anxiety. The rumination led to further thoughts around questions such as "*what if it was too advanced to be treated"* (P7). It is generally accepted that a diagnosis of cancer is a highly distressing event and the most prevalent time of need (reported by participants who went on to be diagnosed with cancer) was the point in time when the diagnosis was confirmed. The shock, disbelief, and change to life made it a difficult challenging time. Participants described it as a period "*completely unknown*" as "*you've never been there"* whilst coming to terms with a "*sense of loss of everything […] your life […] and everything else"* (P18).

The shock and disbelief can have a disabling effect, causing instability and an inability to focus "*can't believe […] I've got Cancer […] I don't know how I'm gonna cope with it"* (P8). There was recognition of the physical impact described as "*like receiving a punch"* (P17) with the inability to "*focus in a rational way"* (P17).

In the literature, there is evidence that anxiety levels in the majority of men decrease after a cancer diagnosis, even when the outcome is not good news (Dale et al., 2005). This evidence indicates a general anxiety-relief value to obtaining results. However, a proportion of men will remain in a distressed state long after the initial diagnosis with facing "*that I was gonna die in the not too distant future"* (P21). Cancer is still a taboo for many men and viewed as a death sentence. The existential threat of death is something which is omnipresent for many men.

Theme 10: Perceived control to plan and prepare

> *"there is something about how we process…how I, keep in control, control is really important to me so […] having some of that element of control, […] difficult because you're not quite in control and you are waiting on stuff […] you can't plan, […] bit of a challenge."* (P1)

One particular aspect of coping, identified by participants as helpful, was problem-focused coping. Being in control of certain aspects of life, when other parts were deemed out of control (such as the uncertainty experienced during the waiting period) was helpful. Recognition of the need to "*keep going"* (P1) whilst recognising *"the emotions"* spilling over as thoughts turned to "*planning […] the things that are important around finances, job, how am I going to manage those things"* (P1). The ability to plan and prepare for the immediate future gave participants focus and a sense of normality. Gaining control through taking ownership of test results was important and waiting for others to give them their 'results' brought frustration and disempowerment described as a "*strange thing"* (P14) considering they are their *"own test results"* and are left to *"wait for somebody"* to inform them to *"know where I stand and […] know what's going to come next"* (P14). Recognition was given to the balance of control within a partnership with HCPs. Understanding the options for the future and gaining knowledge around when to expect information helped to alleviate some of the frustration and anxiety, particularly when faced with a diagnosis, described as feeling "*prepared for the diagnosis when it arrived"* (P13). The support of the clinical nurse specialist presented a *"range of options"*, with practical opportunities to alleviate anxiety and distress such as a *"look around the Department"* so that "*we could get on with it quite quickly"* (P13).

Theme 11: Ability to plan and prepare for next steps and the future - wider than health

Action-orientated coping for the potential future gave participants a clear purpose which was appealing to them:

> *"my feelings were directed towards practically what would I do if I got this sort of situation and […] practically, issues at work […] do I retire quickly and things like that."* (P5)

A pragmatic, structured approach (consistent with a preference for problem-focused coping) appeared to enable participants to focus on practical issues related to coping such as "*how am I going to tell people"* (P1). The notion of planning in steps and stages, with an ending, was felt to be useful to ensure a manageable process, Participant 9 spoke of being "*mindful and broke it down"* and likened it to a pregnancy by having to "*go through a lot of pain and discomfort but the end result will be amazing".* Participant 22 recalled how he began planning for his family's future:

> *"In terms of provision for my family […] Its not just me I've got 3 children and a wife. Ok, now what about them. What do I need to do to make them safe, so you start thinking ok, if its not so good, how are you set up financially. No mortgages, loans, bills. You go back check your, you get in touch with your Union and you think about what cover have I got. Have I got any while I'm in work. And then you start thinking how do I want to be buried. Do I want to be buried or cremated? All these things just spin in your head […] So you start of thinking of the immediate series of practicalities.* (P22)

The ability to plan was also used as a cognitive tool, as a welcomed distraction technique when presented with difficult news *"right it's cancer […] my wife was saying, you were trying to work out the fixture list weren't you from football. Trying to work out what games you were gonna possibly miss."* (P15)

Theme 12: Having an 'outlet' for releasing anxiety and worry

Participants spoke about having an opportunity, or outlet, to release the emotions they were experiencing:

> *“a period of depression […] on a Saturday morning ‘cause I was finding it hard to sleep. ‘Cause I wasn’t working, I hadn’t gone to work and I went for a walk on Saturday morning about half five and I came back and about half seven and I sat in the garden and I just started crying and I didn’t know why.”* (P15)

The ‘safe spaces’ were times when men were on their own, reflecting on their situation, and felt it to be acceptable to release the emotions they were experiencing. Sometimes not knowing why they were crying, but acknowledging the possible relationship with adjustment and change (work changes, difficulty sleeping). The opportunities, such as at work or in the garden, facilitated the expression of emotions that was difficult to show infront of other people. Participants spoke about how emotions impacted on them, when the opportunity to think about their situations arose, and spoke about the benefit of having ‘safe spaces’ for:

> *“moments where you get, you start to well up a little bit and […] when I’m thinking about things in the car on the way back from site visits and […] its difficult to, I find it difficult to… show feelings”*

Theme 13: To have a distraction such as work (paid or voluntary) or events

> *“I’d got a full time job and a family so not a lot of time to sit around and twiddle your thumbs and worry […]. I’d have been annoyed at the prospect of having time off work”* (P11)

The use of distraction, emotion-focused coping, was prevalent. Work and being productive was cited as the main activities for distraction, with the additional benefits of social connection and a sense of purpose. Work has been cited as being integral to many men’s identity, as the concept of work brings incentives over and above financial gains. It is used as a place of normality when other aspects of life seem uncertain and in flux. For those who had retired from paid work, the distraction of voluntary work, hobbies, holidays and wider family commitments were valued and gave purpose and meaning. Participant 15 recalled when his family arrangements changed and “*took precedence over my illness”*, with the added distraction of his grandson coming to live with him who *“was six at the time […] was a bonus. […] I do like spending time with him”.* Therefore, the distraction of wider events helped with “*quite a bit going on that took my mind off actually being ill”* (P15). Work facilitated a necessity to keep busy and gave participants space to adjust to the psychological upheaval experienced. It enabled a vehicle to channel thoughts during a time of distress, helping to manage thoughts which transitioned between “*wildly optimistic* *to wildly pessimistic"*, whilst trying "*to put it at the back of my mind. I couldn't stop working"* (P2). Work helped to ensure participants didn't *"get obsessed"* (P2). The testing and procedures for many participants was viewed as an inconvenience to normal life and hindrance to a productive and full quality life feeling "*this is going to get in the way of other things"* (P10) with a desire to "*get on with it"* (P25).

Theme 14: To postpone the anxiety and deal with it in stages

The ability to postpone anxiety and deal with it 'as and when', at different time points, was found to be a helpful strategy. Participants described putting the results to the "*back of my mind"* (P5), leaving them there for "*a couple of weeks"* to deal with when *"I'm gonna get that result"* (P5). There was recognition that some men used a strategy of delaying worry until the demands necessitated it as "*it's no good worrying about it for a week beforehand is there?".* Participant 9 recalls dealing with it in stages by breaking it down:

> *"everybody just lumps everything together. And if you can take things on in bite size chunks and instead of saying right, I've got to have this done, that done, and that well actually, this week I'm having this done so lets address this and see what the outcome is of that and dealing with it that way"*

Other commitments took priority to individuals' own thoughts because of the circumstances they were living in. Participant 12 shared how he cared full time for his wife with Alzheimer's disease and disclosed how he was "*under huge stress"* and therefore "*wasn't really thinking of myself at the time"* due to *"so much responsibility".* He described how he carried a "*mass of emotion and turmoil inside".* Delaying the anxiety was recognised as helpful for a short time but was recognised as needing to be faced up to eventually, especially at diagnosis. However, other participants illustrated the impact of delaying thoughts about cancer by feeling "*naïve"* (P15) when the cancer diagnosis was given with recognition to it being a way of coping "*to deal with it"* (P15).

Theme 15: The use of humour to lighten communications

The use of humour aided camaraderie amongst peers going through the same experience. As a way of coping and dealing with the anxiety of waiting:

> *"to be honest, my wife and I thoroughly enjoyed our time […] particularly the black humour of our fellow sufferers. The Waiting Room for instance was known as the Departure Lounge because a lot of us wheeled out in our dressing gowns in these poor old bags […], baggage that you could put in an aeroplane […] some of the*

> *people […] were not going to survive […] our waiting room became known as the departure lounge […] humour was terrific. I wish I could encapture all of it."* (P10)

It provided distraction and a way to express and communicate difficulties providing inspiration with peers *"who deal well with problems"* (P10). Humour co-created with peers built a collective sense of relief for the individual and for their family and friends too. Making light of a situation through humour gave the ability to control the experience in a manageable way. The sense of determination and solidarity delivered surreptitiously via humour was appealing to participants.

Participants talked about using humour as a way to cope with serious or embarrassing situations, such as when discussing cancer testing or a diagnosis with others. Humour was used to help them deal with tense or challenging feelings of anxiety or embarrassment. Participant 9 talked about waiting with another man who had *"been sat there waiting for 8 hours […] to go home"* and they were managing the time by "*joking*" saying *"let's take a nurse hostage and dig a tunnel and […] get out."* Humour enabled men to talk about experiences that were embarrassing or sensitive in a socially acceptable way. It reduces the psychological impact of the situation to a less threatening one, making the experience more manageable. Participant 15 added how at work he would ask the "*lads"* to check *"down below"*, highlighting how it lightened the situation of his suspected testicular cancer as he added *"nobody wanted to check as you can understand but we were making light of it".*

Healthcare professionals can act as moderators during stressful episodes. Participants welcomed the use of humour from HCPs to lighten consultations and offer reassurance. This brought the relationship of 'patient and practitioner' to an even level, reducing the tension and hierarchy using language such as *"bugger all"* (P17) which provided *"music to my ears."*

Theme 16: Dealing with uncertainty

Certainty of events provides individuals with control. The ability to understand what will happen next is comforting and reassuring. When someone is confronted by a health threat that poses a risk, such as a diagnosis, it has the potential to destabilize. Uncertainty of future events can provoke anxiety and many participants who were awaiting test results experienced apprehension and anxiety about the results and their potential impact:

> *"the uncertainty of when will I get a letter from the hospital, when will the appointment be, and not being in charge of my own life like. Can I book a holiday? When can I get back to my normal pace? That was out of my hands and I didn't like that […].The delay and not having information about it causes more people anxiety than anything else I think." (P6)*

Participants described feeling "*wound up, anxious, depressed"*, *"apprehensive, worried"*, *"scared"*, *"frighten[ed]"* (P8, 12, 18) whilst also anticipating the future: *"have I got Cancer […] what's going to happen after that?"* (P4)*.* The period of time waiting for the results of tests to confirm cancer can be described as being in '*limbo*' (P21), not ill but no longer deemed healthy. They waiver between the potential of illness and anticipate disease whilst being asymptomatic "*it could be something or nothing"* (P21)*.* When the waiting period is over and the results are given, men identified being diagnosed with cancer as a highly distressing event. Participants recalled feeling "*shocked, really shocked",* which affects the ability to *"focus in a rational way"* (P17)*.*

Theme 17: Psychosomatic impact on physical health

> *"I was obviously having an awful lot of tension and that was leading to […] severe […] back pains. […] convinced that something is happening […] I had a bit of time to think […] I woke up in the night just some convinced you know that I was, that I definitely had got something in my bones, you know and that obviously probably would be mean a shorter life expectancy"* (P5)

The power that the mind has over the body is one which was recognised by many of the participants interviewed. Somatization is the expression of personal and social distress and relates to the process by which people with psychological distress experience physical symptoms in the absence of any organic cause (Kleinman & Good, 1985). During the waiting period, participants spoke about the effect distress had on them physically, as well as mentally. Participants experienced *"pain"* (P24), "*tension… pains"*, (P5) which led them to believe that the diagnosis would be confirmed as cancer and was spreading. Participants spoke about being "*convinced"* (P5) that it was in their *"lungs"*, *"everywhere"* which made the waiting period feel "*long*". Feelings of uncertainty appeared to impact on individual's thoughts during the period "*you don't know whether you have just burst a blood vessel take it easy for a month and you'll be fine or whether it […] cancer that's likely to kill you*" (P21). Participant 24 described the process of how "*you can have an itch on your hand and you think its another symptom of cancer…You have a headache and you think oh gosh I've got a brain tumour".* Participants acknowledged the reality of the thoughts and feelings: "*it's stupid. But that's how you feel. Anything different you think it's* *a symptom"* (P24). The tension caused by the anxiety was something which manifested itself in physical symptoms.

Theme 18: A lack of confidence and support to self-manage

> *"I feel that theres not sort of enough information to keep your prostrate healthy […] to keep it healthy […] to stop any cancers growing. I would have appreciated some more […] things to sort of keep it healthy but I couldn't find anything"* (P8)

Participants spoke about a desire to self-manage at different stages of their experience. They reported feeling conflicted and lacking self-efficacy to understand what was considered an appropriate level of management and within what time period. Physical activity was an area of confusion, as Participant 15, who was a regular gym user, was told "*do whatever you want to do but don't overdo it."* He described his confusion "*how will I know if I've overdone it?"* and recalled how "*no one can give you a definitive level of where you should be. 'Cause everyone's different".*

There was recognition of the need to learn self-management skills to manage anxiety and stress with support from a healthcare professional. Understanding where to go to access credible information to enable optimum self-management was another identified area of need, as Participant 21 explained his desire to "*have had some information given me so that I knew what was trustworthy if nothing else"* in addition to support from somebody to "*give you some advice, or just direct you to a couple of decent websites and say ignore the others."* He was concerned about knowing what was "*reliable and what was not"* at the time. Recognition was given to the partnership approach to self-management support needed between the healthcare professional and themselves. There was acceptance that there comes a point in time where the support (with choices and options) given by the healthcare team reduces, and it is time to take the initiative. Participant 24 described "*you've got to do it for yourself"* and likened the process to a bus journey, stating that the bus driver isn't going to "*come knocking at your door to tell you the bus is outside is he? At some stage you've got to get out of the chair and walk to the bus stop, and if you don't that's your problem."*

Taking charge and being prepared is something which many participants cherished and thrived on. After the initial stages of shock and disbelief, participants who received a diagnosis talked about how they managed the process of preparation, gathering their thoughts and questions before going into a consultation with a healthcare professional:

> *"The communication side of it, in the end […] I was taking questions in with me and the first thing the Consultant was doing was taking the list off me and answering those before he'd go into his normal conversation".* (P16)

Support and advice with specifics around *"diet"* and keeping healthy were identified as a need and a gap in support *"good to get a bit more advice […] to know you're doing the right thing"* (P5).

Theme 19: Issues of masculinity, stoicism and cultural expectations

Participants disclosed how admission of personal difficulty can feel threatening for men and perceived by some as a sign of weakness:

> *"blokes tend to say, ok, lets get on with it, I don't want to know or they don't want to know in the first place. […] want to be supported […] pretend they don't want to be supported perhaps but they don't want to admit to it and it needs for blokes to get the impression of look I'm worried to death about this, its frightening me to death […] That doesn't make the bloke less of a bloke. We should admit to feeling worry. […] and I think they just don't like to admit it. Men in general don't like to admit they need help. Its going back to the old battle days, you're the big strong lad, you can take it."* (P25)

Acknowledgment was given to how some men view help-seeking as illustrating a need for dependency and dismissing the masculine 'ideal' traits of self-sufficiency, strength, bravery and stoicism. Participants recognised issues relating to men's *"macho level"* (P9) and being perceived as *"a wuss"* if they asked for help. They claimed it may impact being diagnosed early, as for some men they may believe "*if I don't go to speak to someone it'll go away"* (P9). They recognised the need to change the dialogue through advertising to highlight to men that it is "*ok to ask for emotional help, […] you're not a whack job, you're helping yourself"* (P9).

Participants spoke about the tension of disclosure being perpetuated by others in society. Even when they were confident enough to communicate their experiences, other people's reaction affects the experience, as stigma is felt, continued and passed on. Participant 16 described how he got "*into a little bit of a hole initially […] and got depressed"* as he recalled wanting to *"tell everybody"* but was limited by other people's perceptions of what a man should disclose to others. He recalled when somebody asked him "*why would you tell everybody what you're going through […] Like being a man, why would you do that?".* The experience left him feeling *"held back from moving forward"* as other people *"on the outside of it that hadn't experienced it"* (P16).

Participants described their perceptions of cultural expectation of what it means to be a man in Western society and their need for objective support during the cancer early detection period. They described the impact that the language healthcare professionals used had on them and the importance placed on it. Participant 2 recalled a military nurse saying to him *"what you crying for man?"*; he went on to describe how the experience impacted on the consequences of the experience as he "*didn't take any painkillers. I managed to get through it".* He recognised the challenges of informing men, as "*men don't deal with health issues well at all"* and believed it was because men identified with being the leader and head of the family "*I am the breadwinner, I am the leader."* He concluded by stating, "*men don't know how to cry, men do not deal with health issues"* (P2).

Certain procedures during testing are intrusive and place men in a vulnerable state handling "*that part of the body"* (P12). Participants talked about coming to terms with a change in sexual activity and their sexual identity with the loss of "*no tomorrow as far as I was concerned for any of the kind of, […] being a normal human being."* (P12). The effect of a diagnosis and potential treatment on sexual function, for certain male cancers, impacted men faced with the possibility of being made impotent which resulted in feeling "*depressed".* Recognition was given as *"it still plays a part of your life"* (P15) *and* "*it's the worst thing you can do to a man"* (P18). Participants described the fear and increased chance of impotency and the impact to what the very core of what a man is "*pretty devastating stuff for a man really"* (P18).

Theme 20: To not 'burden' others and selective disclosure

Participants experienced a dilemma concerning how to pitch going through testing for cancer in their communication with others:

> *"not wanting to burden people, […] not wanting to talk about it and that's probably not a great thing? Probably not a great thing…But the question is who would I speak to […]? You don't want to turn it into a drama" (P1)*

Other participants chose to be open with everyone, whilst some revealed information to a select few; and several kept it to themselves until they had more information. The need to not burden other people with the information until absolutely necessary is a phenomenon that several participants experienced. Participant 1 described not wanting to worry others, wanting to manage by himself. He likened it to "*being a hero"* by *"doing it on your own"* and suggested that being single "*I think it's different when it's your partner, […] you can* *share that load".* Men on their own expressed a need to "*face up"* (P15) and find the best way to *"get through"* (P2) the cancer early detection period.

When a diagnosis is given, participants identified a need to find a way to communicate the news to those who may be more vulnerable due to factors such age or circumstance (such as children or elderly parents). Participants acknowledged the feeling of anticipation and expectation as they pre-empted the reaction of their family members especially those who had other family members with cancer "*my brother, 6 weeks earlier had been diagnosed with leukaemia and my Dad had Bowel Cancer and […] both my Mom's parents had died of it."* (P18). There was reticence about approaching the subject, and participants identified cancer as being a topic people do not want to talk about. Participant 8 recalled how he didn't have family to support him, just friends, and described not wanting to "*approach the subject"* because people "*don't want to know other people's medical problems"*; this reluctance resulted in not having "*anybody to go to talk about it."*

To be independent and capable was important to participants. There was reluctance to be seen to need the help of others, especially for those used to being in control or asking for help. Participant 14 described how his wife didn't go with him to any appointment because he "*needed to do it by myself"*. He described how others viewed it as "*hiding something"* from his wife, to which he added *"I certainly wasn't."* The need to be self-reliant and stoic in the face of adversity was important for participants faced with a health threat to their bodies.

Theme 21: Gender of Healthcare professionals involved in care

The gender of the healthcare professional played a role in the perceived consultation style, and this affected the experience for participants during the cancer early detection period and at diagnosis:

> *"One of the things that stuck in my head […] that set me back, […] was the way I was told about my condition. I'm sure if I was a woman and I was to be given that information, I think it would have been done differently. I think from a perspective of Doctors and Consultants like you know, when they inform men about something like that they do it differently. They do it in a macho style you know what I mean rather than the gentle approach. […] Most men aren't likely to burst into tears. Its not macho to do that, and I think Doctors, especially men giving men that kind of news to other men then trying to be like, […] the macho type approach, […] Rather than the sensitive approach."* (P6)

Reference is made to the pereceived difference in communication style of the ‘macho’ approach of male doctors or consultant and ‘sensitive’ approach of female medics. Other accounts gave detail of how they could perceive the emotions of the professionals involved in their care and how that impacted on their experience. Displayed through their actions during consultations, men observed closely the emotions of healthcare professionals, such as embarrassment. Participant 9 talked about how he perceived the male clinician was “*embarrassed”* and after he had delivered the diagnosis he “*just slipped away. There was no offer of emotional support”.* He described how he felt that the clinician *“wanted to […] but he thought he couldn’t so that’s why he’d delegated it to the nurses”.*

Theme 22: Risk perception communicated by Healthcare professionals and trusted others

There was recognition of the significant role that ‘trusted others’ made in decision support and risk alongside the healthcare professional’s input:

> *“there was support from the Nurse, the Specialist Nurse in terms of these are your options, but (they) never actually gave me any advice as to which one I should choose. They gave me the facts and it was down to me to make the decision. […] I was lucky at that point as […] various friends knew, I kept that to a fairly select number […] (I said) I’ve got these options and I think this is the right one, and a couple of them did actually say are you sure you really want to do that? So it was good to have people that actually questioned my logic because I think I wasn’t always particularly logical at that time. Or sensible in many ways”* (P21)

Having the opportunity to talk through perceived risks and decisions with trusted others provided an opportunity to question, reflect, and gain insight from others during a time when it was difficult to independently think clearly or logically. Thus, safely discussing concerns may provide new meanings and help to assimilate the cancer experience:

> *“talked to people I knew, you know, colleagues, ex-colleagues of a similar age or friends and found a couple of those that had been or were going through the same process […] interesting to […] share notes with them.”* (P4)

In addition, the communication between participants and healthcare professionals caring for them during the cancer early detection period had an impact on their cognitive state. Participants looked to healthcare professionals for credible information and appreciated the use of plain English and layman’s terms to aid communication, understanding and avoid unnecessary misinterpretation. Participants described frustration and a need for "*lay man's language"* (P8) because *"medical language"* (P8) used prohibited understanding with recognition that *"easier words"* (P8) would enable individuals to have *"understood it more"* (P8). The way risk was communicated to participants had an impact on their waiting experience. For many, the communication of hope (of a low risk of cancer) was welcomed and allayed fears in period. However, others, such as Participant 3, recalled it not being a "*period of anxiety at all"* due to the GP's communication indicating *"I don't think its Cancer"* and so he was not *"unduly concerned".* HCPs are in a position where they have to delicately negotiate and ensure tailored information is provided whilst maintaining hope, which is made more challenging when forecasting the future. The balance is recognised by participants as difficult and potentially risky as false hope can lead to additional issues of confusion and conflict. Participant 21 recalled how false hope was given by a GP and nurse, before a cancer diagnosis was confirmed, as "*almost everybody said, don't worry about it, it won't be, it can't be cancer you're too young."* Providing clarity of information and using honest, open communication, without false hope was appreciated. Where ambiguity arises, it leads to further issues of confusion and concern. Participants talked about not wanting to be shielded from the truth by HCPs and to be able to understand what is happening at each stage of the process with honesty if there was concern about anything such as *"some suspicious cells"* (P2). Participant 2 was provided with reassurance but felt confusion when the consultant stamped *'Cancer'* on the X-ray form and added *"I've got the wrong stamp today don't worry about it".* He claimed that *"it will fast track it through the system".* He was left feeling angry and wanted "a *little bit more honesty"*, adding *"if they suspected it was cancer I don't know why I wasn't referred immediately [...] was someone embarrassed about the diagnosis?".*

Theme 23: Communicating the results of the test

Unsatisfied participants spoke about the professional's perceived need for speed and a lack of time within the diagnostic consultation. Words used to describe the experience included 'brusque' (P17), 'short and sharp' (P9), 'brutal' (P18). Participant 9 talked about how his experience left him feeling emotionally upset, as after a rushed consultation:

> *"I looked at him and said "is that cancer?" and so he said "well, I can't tell yet but I'm quite confident that it is" and then I said "well, ok, what happens next?" and he said "well, we'll prepare a course of treatment for you , we will get back in touch with you, you're ready to go, free to go whenever you'd like" and with that he just disappeared and […] I must admit I burst into tears" (P9)*

Participant 6 recalled how his consultant was very "*matter of fact*", with a lack of "*information*" and *"process"* of what was going to happen. He perceived the consultant's attitude to be dismissive and cited "*go away and we'll be in touch with you".* There is an increasing amount of literature that suggests that the way that cancer test results are communicated has fundamental consequences on the individual's health outcomes, including their: experience of distress; recall of information; satisfaction, and; level of trust in the healthcare professional (Arora, 2003; Butow, Dunn, & Tattersall, 1994; Robinson et al., 2008; Roter et al., 1995; Schmid et al., 2005; Sep et al., 2014; Spiegel et al., 2009; Tulsky et al., 2011). If subsequently a cancer diagnosis is given, the way results are communicated can also affect an individual's adherence to future treatment (Burgers, Beukeboom and Sparks, 2012). Two participants spoke about their experience of being told they had cancer whilst still on the examining table. One man spoke about how the instrument detecting the cancer was still in situ of his genital area when he was told. On reflection of these experiences, both men described how it could have gone better. Participant 21 recalled *"the most surreal feeling"* to be given the results with a tube in situ in the bladder and then the *"camera pulled back out"* and then "*literally sort of shown the door".* Acknowledgment was given to how the experience could have been improved with being asked *"are you ok, do you want to have half an hour to just sit. And do you want a cup of tea".* One participant spoke about how his experience could have been improved by not only being off the procedure table, but also being given the option to take someone into the consultation, as way of support and also as an aide memoire. Some men identified this as a need as they were not given that opportunity. Participant 12 recalled "*I think he might have brought my Son through or taken me to another room or got me off the table".*

With regards to the role of the HCP giving the test results, the large majority were given their results by an Oncology Consultant. A minority were given them by a: General Practitioner; Oncology Clinical Nurse Specialist; Specialist Consultant (for example ENT specialist). All of the men who were not given a diagnosis of cancer were satisfied with the way the results were communicated to them. Of those men who went on to receive a diagnosis of cancer, eleven were satisfied with the way the results were communicated;

> *"yeah, really, really happy with it. I couldn't fault the way it all worked for me […] the communication side of it"* (P16)

Lay man's terms aid understanding and balance out any perceived hierarchy or power imbalance. Concern was expressed that the term 'cancer' is not being used explicitly by all healthcare professionals, leading to increased misunderstanding and uncertainty.

Several participants reported not learning about their cancer diagnosis until sometime after the initial diagnostic consultation had been given, due to their lack of understanding around the terminology used. The instances where the term ‘cancer’ was not used led to confusion and misunderstanding. Participants recalled the presence of cancer being referred to as a *“lesion”* (P25) and a *“mass”* (P20), which added confusion whereas “*it would have been better if he’s said ‘cancer’* (P20)*.* For those who went on to receive a diagnosis of cancer, the communication of risk continued to play an important part in their experience, especially around the next steps after diagnosis.

Theme 24: Effective, honest and open communication from Healthcare Professionals

> *“the doctor […] she explained the stuff she was very good she was very sensitive, I really liked her, her style she was calm and made time in the clinic, the busy clinic actually she made time so I didn’t feel like I was being rushed […] I was really happy.* (P1)

Given their underlying emotional state, communication for participants during the cancer early detection period was fraught with difficulties and tensions. Participants described an optimum consultation as one where: the healthcare professional had created a safe and warm space; they felt comfortable; they were in rapport with the professional, and; they had the opportunity to explore issues without any perceived boundaries. The opportunity to communicate in a safe environment with healthcare professionals in an upfront, to-the-point manner with compassion was welcomed. The participants who were satisfied with the way in which the results were communicated valued the opportunity to have time and space with the healthcare professional to talk about the results in more detail once the diagnosis was given. When this optimum approach was not experienced, participants recalled the appointment in great detail, including: the body language of the professional; the words used; how it made them feel; and the impact.

The limitation of appointment time for consultations can lead to dissatisfaction with *“no warmth or real connection between the Consultant”* (P17). Participants tried to mitigate for these deficits. One participant subsequently paid privately to see him for further information resulting in him feeling *“more enlightened and more relieved […] more upbeat about everything”* (P17). He believed that receiving a diagnosis as an NHS patient limited the scope to be able to demonstrate *“any great depths of humanity”* as *“it’s very clinical”* (P17).

Delivering bad news is part of the healthcare professional's role. Participants spoke about having empathy towards those who had to deliver the bad news of a diagnosis as they could perceive the emotions of the HCP and observed the body language:

> *"clearly very uncomfortable having to do it […] He just didn't know how to do it. Terribly, terribly it was clear that not only was he clearly uncomfortable aspect of being told was his embarrassment. He was almost on the verge of running. He couldn't get it over and leave quick enough".* (P10)

Recognition was given to the complexity and difficulty in communicating difficult news. The need for the professional to disconnect emotionally was identified, and men welcomed factual, to the point confirmation. Participant 21 recognised that although it was direct it was what was needed: "*it was a bit blunt. But how else do you tell someone?".* Men picked up when healthcare professionals were not comfortable and the consultation was compromised. In some cases, the situation was made worse by the healthcare professional's inability to communicate a diagnosis effectively, using language and statistics inappropriately to mask their own emotions. Participants recalled *"little eye to eye contact"* (P17)*,* with the use of *"smoke screening, quoting statistics and figures, all of which are meaningless at the time",* with a desire to just say "*tell me the news mate. That's what the patient wants to hear".*

Communication between men and their healthcare team is a multidimensional process which includes the concrete content of facts, information and the emotional component. There is recognition that at a time of heightened emotions and ambiguity there is potentially more room for misinterpretation or misunderstanding, without the confidence to double check for accuracy. Participant 17 recalled how he thought the prostate was cancer free and did not realise that what was actually being communicated was that there was "*no cancer in the samples that were taken".* Upon reflection, he felt that the test's limitations should have been explained more fully whilst recognising *"you hear what you want to".*

Theme 25: The role of HCPs and trusted others in instilling hope and confidence

The way in which the diagnosis (and prognosis) was framed, and the language used by the healthcare professional and trusted others, has an impact. A positively-framed prognosis was reported as bringing hope for the future and received better by men than those who reported a negatively-framed prognosis. Participant 6 recalled how his 'trusted others' were his daughter's friends, who were oncologist nurses, who gave him hope by sharing "*its one of the better ones to have if you're going to have Cancer"* and how it *"eased my mind".* Similarly, Participant 15 recalled how he was eased by the positive slant given as "*they stress the positives of it […] if you're gonna get cancer it's the best one to get"*, aided by them not painting a *"doom and gloom picture*"*.* The other valued strategy was a positively front-loaded communication which improved the consultation. Participant 6 described how his experience could have been improved:

> *"he could have started off by saying, 'the good news is your tumour is confined to the bladder. […] we're going to give you treatment', […] I would like to have had the process outlined, do you understand? Like a Roadmap. […] like him to have given me a Roadmap. So I could be in charge of my life again".*

Participants looked to healthcare professionals for credible information to help them to prepare and manage their expectations for the future. Participant 5 recalled how his doctor reassured him by telling him positive stories about other patient stories. The doctor said "*if it does go into your bones […] I had a patient at my old place […] who's still coming to see me 12 years on."* He reflects on how the waiting period was eased by the comfort given, as a lot of what the doctor said to him made him "*feel a lot easier waiting."* Participants highlighted the important role of the healthcare professional in negotiating tailored information whilst instilling hope, confidence and reassurance, as it was believed to be fundamental to how the situation is perceived. Words of encouragement from professionals were welcomed by participants, phrases such as "*don't worry about it, if it is what we think it is we'll look after you"* (P6). Advice such as "*remain very positive about it"* (P9) helped participants through the cancer early detection period.

Participant 5 talked about how he had gained hope and confidence from trusted others who, even though they were 'living with cancer', are having a better quality of life post diagnosis:

> *"a good friend who's had lymphoma or leukaemia some version of leukaemia for about six or seven years now and she basically stopped her job and her husband got made redundant so they're floating round the Med at the moment in a boat and that's how they live their lifestyles so she writes a blog and […] a positive sort of person […] so that's quite comforting aswell.*" (P5)

Participants want information which is factual, honest and delivered directly to them in a way that is supportive and compassionate. The area of communicating prognosis is delicate due to the challenges of forecasting the future and its impact on considerations of mortality. Participant 18 recalled how his consultation was *"unnecessarily brutal"* due to being given *"information I would have been better off not having at that time".* He wanted to get over the initial shock and concentrate on what was going to follow but felt it was unnecessary to "*go on to tell me that if it had spread there was no cure for it, I think that* *was a little bit silly. I didn't really need to know that at that time".* The need to communicate hopefulness was considered important in the cancer early detection period, even more so when the prognosis was poor. Other professional roles compensated for the communication deficits of some, and the presence of a nurse had a positive impact. Participant 10 recalled how he was passed on from the Urologist *"who had the communication skills of a goat, to a splendid oncologist who was excellent in communication".* He explained how the nurses compensated for the urologist *"rather well*" and the "*Oncologist […] was very open and very communicative really understanding".*

Communication of information by a knowledgeable professional delivered in a sensitive, calm and compassionate manner, with time for questions and queries, gave an optimum experience. Participant 19 described how there was nothing to "*sort of hide"* or *"to cover anything up […] He told me straight away".* When participants felt in control and able to take the time to question, and explore options and issues with, the healthcare professional, they experienced feeling more confident and informed.

Discussion

The aim of the study was to understand the experiences and needs of men in relation to the cancer early detection period. The findings generated twenty-five themes, building insight and understanding of the core concepts of men's experiences and identified needs in relation to the cancer early detection period.

Relating the themes to the wider literature

Participants who had a readily accessible social support network, which they viewed as being socially acceptable to discuss their health issues within, reported the benefits it brought to them psychologically. The social connection gained was comforting and enabled them to manage their emotions better. Trusted relationships and access to a supportive individual, usually a partner, were key factors in a participant's ability to cope, as the option of support from them alleviated distress and enabled them to cope better. Numerous studies report the important role that close family and friends play in prompting men's engagement in identifying a need for support or helping to access and navigate information (Baird & Pearce, 2001; Corboy, McDonald, & McLaren, 2011; Dickerson et al., 2006; Dickerson et al., 2011; Evans et al., 2007; Gray et al., 1996; Seale, Ziebland, & Charteris-Black, 2006; Wallace & Storms, 2007) and specifically within the prostate literature where partners, friends and families are described as significant sources of support (Boehmer & Babayan, 2005; Ervik, Nordoy, & Asplund, 2010; Matsunaga &

Gotay, 2004; O'Shaughnessy et al., 2013a; Rivers et al., 2012; Walsh & Hegarty, 2010). Therefore, these findings extend existing current knowledge beyond prostate-specific research highlighting social connection needs, within the cancer early detection period, across different tumour sites and diagnostic outcomes.

The results confirmed that participants valued peer support and accessibility to people with a lived experience of cancer. The opportunity presented time to learn from others with a lived experience, gain support and accrue further knowledge and information. The valuable benefits were highlighted as important to participants, giving them confidence, reassurance and a clearer understanding about the process. These findings corroborate with King et al.'s (2015) study, which found that peer support helps men to express their experiences of illness, and share knowledge and thoughts, making them feel less isolated.

The opportunity to talk and share was experienced as empowering. Galbraith, Hays and Tanner (2012) describe how peer support provides a sense of meaning in men's experiences. The findings highlight an unmet need in relation to support for isolated men. Participants without a supportive individual, who lacked social support were disadvantaged in using a social support network as a means of coping with the threat of cancer. This suggests that men without social connection may be at greater risk of experiencing distress during the period and builds on previous research which has illustrated the vulnerability of those without a partner (Konski et al., 2006; Wilson & Oswald, 2005). Therefore, the ability to connect socially (by building on existing networks or connecting with services for social support) provides the potential to enable isolated men to cope more effectively. Men at higher risk may benefit from being signposted to sources of credible peer support and information (that they can access as and when they need it). The sources could be via several different accessible forms (including support phone lines and online forums, interventions).

There is also the potential to bring benefit through the connection of a shared experience to normalise the illness experience. A recent study conducted by Wootten et al. (2015) found that combining online peer support, with CBT, was optimal for reducing distress in men with prostate cancer. This supports previous studies of in-person delivery, where education with peer discussion was found to be the most beneficial (Lepore et al., 2003). Peer support can play an important role in supporting men who have cancer (Duffecy et al., 2013; Wootten et al., 2015), but there is a gap in the literature during the diagnostic period (Brown, Oetzel, & Henderson, 2016) that this study adds valuably towards.

When participants were waiting, and knowledge of the outcome was limited, individuals experienced feelings that challenged important aspects of their lives. The benefit of accruing information and knowledge, to support independence and a sense of control, were highlighted as important to participants. In line with the literature (Leydon et al., 2000, Wiljer et al, 2012, 2013), many wanted information about cancer and the opportunity to learn from a variety of sources, as information needs were diverse. Having pertinent information in the period before diagnosis has been shown to increase confidence (Valanis & Rumpler, 1985), reduce anxiety (Dodd, 1988) and assist in accepting diagnosis (Sawyer, 2000). This highlighted a common unmet need in relation to receiving support to navigate to credible tailored information sources (as participants reported not knowing where to access quality resources) and the flexibility to acquire information at the right time of need. Providing the option to access credible literature, particularly about the cancer tumour site being tested and the emotional aspect of the waiting period, has the potential to provide reassurance and a sense of control to enable coping and effective management during the period. The ability to develop insight and information about the next steps has the potential to buffer against stress (Helgeson, 1992, 1999; Henselmans et al., 2009b; Penninx et al., 1996).

Many participants were keen to access quality assured resources at their particular time of need. Comfort was gained from having the option to talk through the information with a reputable source using a person-centred approach (such as information manager at the cancer centre or Clinical Nurse Specialist). The accounts give weight to the impact that accruing credible knowledge and information have by enabling individuals to feel reassured and a sense of control at a time of anxiety and apprehension. Therefore, these findings suggest that supporting and preparing individuals with accessible resources and credible information is crucial to the comfort and reassurance it brings during this stage. Studies on the needs of people affected by cancer, at diagnosis, have found that information provision could be improved to support the self-management of health and individuals' wellbeing (Majumder et al., 2014).

Interestingly, participants identified the internet as the first 'port of call' for further information, accruing knowledge and support during the waiting period. Using the internet to access information and support is appealing for many men for several reasons. The anonymity and flexibility of using online resources gives individuals the freedom to access support at a time and location convenient to them. It can be accessed 24/7 and has the option to present information in a format that is easily tailored and personalised to the individual (Beatty & Lambert, 2013; Leykin et al., 2012). Recent studies have found web-based interventions to be promising mechanisms to deliver education and information to meet the needs of people affected by cancer (Lubberding et al., 2015; Ventura, Öhlén, & Koinberg, 2013; Wheelock et al., 2015; Wolpin et al., 2014). In particular, Galdas and Baker (2015) highlight the important opportunity the online environment presents to support men's emotional needs without compromising their masculine norms (such as stoicism) (Robertson, 2007; Pollard, 2007). These findings highlight the opportunity that exists for the use of the internet, as a mechanism for holistic support, for future men to gain information and knowledge during the cancer early detection period.

Participants reported using several different coping strategies - in response to the appraisal of the threat of cancer - to manage the emotional aspects of uncertainty and anxiety experienced during the period. The strategies used were divided into 'problem' and 'emotion' focused strategies. Participants identified the value of the strategies in providing: feelings of being more in control (through planning); a release of emotions (crying); purpose and status (distraction); the ability to break it into manageable stages (compartmentalising), and; a lightening of perceived burden (humour). Interestingly, many of the techniques focused on the 'management' of the period and were focused heavily on problem solving. This fits with a plethora of other studies that have highlighted men's preference for problem focus coping (Dale et al., 2004; Klemm et al., 1999; Sharf, 1997). However, the findings also add to the literature on men's emotional experience of the cancer early detection period in several ways. Numerous studies reveal that emotional approach coping (EAC), can enable positive adjustment for individuals with breast cancer (Giese-Davis et al., 2002; Hoyt, 2013; Manne, Ostroff, & Winkel, 2007; Stanton et al., 2000a). However, there has been very little research on men in this regard (Hoyt, 2013; Meyer & Mark, 1995). The findings from this study highlight that, within the range, participants also adopted emotion focused coping, to enable them to self-manage during the period. It is interesting that the EAC strategies were expressed and processed when participants were on their own. An example is through the strategy of releasing emotion through crying in a safe space, participants talked about allowing themselves to cry when they were on their own. This fits with the need to not burden others and protect their perceived masculinity. Timing of the strategy was important and chosen to ensure that no one else would know — it was protected time. This adds to the field of understanding around coping strategies used by men and highlights the opportunity for future studies to build on and explore men's emotion-focused coping strategies in more detail.

Supported by previous studies (Lepore & Revenson, 2007), this study confirms that the waiting period provides problems in communicating with others, and many of these relate to conceptions of masculinity. Several participants wanted to be viewed as independent, capable, not a burden and many referred to holding off disclosing issues until crisis point. The rationale given was mainly to protect vulnerable others (children and elderly parents) until it was felt to be absolutely necessary to disclose. Some participants chose to keep the potential diagnosis to themselves until they had more information, others revealed elements (to close friends and relatives), and some were open and shared with everyone, aligning with previous research (Bloch et al., 2007).

The study illustrates links between communication tensions in the cancer early detection period, issues of masculinity, and the impact on participants' perceptions of the experience. Participants disclosed an awareness of how personal difficulty can be viewed as a sign of weakness and dependency which goes against masculine ideals of self-sufficiency, strength, bravery and stoicism. Therefore, expressing distress or seeking support may be viewed as disrupting the notion of their identity as a man. A proportion of men acknowledged the additional threat to sexual function that the period brought (especially cancers of or near the genitalia). The findings concur with the literature indicating that seeking and accepting support can pose threats to men's identity (illustrated by self-sufficiency and independence) (O'Brien, 2005), resulting in a need to justify involvement, in order to preserve identity as a man (Seymore-Smith, 2008). This indicates that in order to meet men's needs during the cancer early detection period, the valid justification for obtaining support needs to be clear. For example, information and support needs to be framed in a way that encourages men to view sources of support and resources as 'building blocks', to enable them to be better able to look after others around them. By taking care of their own needs they are better able to protect the more vulnerable others they look after i.e. 'doing it for others'. This finding has implications for the way in which information and support is presented to men during the cancer early detection period in the future.

Participants highlighted the high need for effective communication with healthcare professionals, to add clarity to improve understanding. This mirrors previous studies (Arrington, Grant, & Vanderford, 2005; Bourke et al., 2012; Oliffe, 2005; Sullivan, 2003) and adds to the research. Recognition was given to the difficulties of communicating bad news and acknowledgment that professionals need to disconnect emotionally to be effective. This builds on other studies' findings (Dennison, 1995; Kruijver et al., 2001) which refer to it as 'blocking' behaviour used during emotionally charged interactions, and a defence mechanism to enable them to cope and preserve their own emotional wellbeing.

Participants valued the use of non-medical jargon, and on occasions when jargon was used (or complex statistics were referred to) participants viewed it as the healthcare professional's inability to communicate effectively. Value was given to the use of lay man's terms, and the word 'cancer', to aid understanding and clarification. This aligns with the work of Schofield et al. (2003), who found that both individuals' satisfaction with the way they are spoken to by HCPs, and less anxiety and depression, were associated with using the word 'cancer', talking honestly about the prognosis, and the impact of the cancer on themselves holistically. This highlights the need for future resources and support, developed for men during the period, to incorporate these important factors to aid clarity and understanding.

If a diagnosis was given, participants wanted factual, to-the-point confirmation with the opportunity to talk about the results. Participants gained a sense of control when they were able to take the time to question and explore options or issues with the healthcare professional, leading to feeling more confident and informed. This adds to the literature, which aligns with the importance of providing individuals with as much information about the diagnosis as they wish for, allowing time for discussion, and presenting the information clearly (Schofield et al., 2003).

Participants in the study wanted a positively-framed prognosis that delivers hope for the future, with tailored information which instils hope, confidence and reassurance, delivered directly to them in a way that is supportive and compassionate. These findings are in keeping with other studies detailing a desire for a compassionate, polite and empathic approach (Carter et al*.,* 2011; Ervik, Nordoy, & Asplund, 2010; Galbraith, Hays, & Tanner, 2012; Milne, Spiers, & Moore, 2008; O'Brien et al., 2010, 2011; Ream et al., 2009; Thomas, 2013; Walsh & Hegarty, 2010). Therefore, the limitation of appointment time for consultations can lead to dissatisfaction, as other studies demonstrate the value of the opportunity to interact with professionals and ask questions (Arrington, Grant, & Vanderford, 2005; Bourke et al., 2012; Oliffe, 2005; Sullivan, 2003).

The findings from this study provide insights into men's experiences of the cancer early detection period and suggest that the experience is improved when several key components are present or activated. The results indicate that being socially connected was related to better management of emotions, resulting in a perceived ability to cope effectively. Having access to a supportive individual assisted with the alleviation of distress, whilst accessing peer support improved confidence and gave reassurance. A reciprocal relationship between talking and sharing was reported as empowering and facilitated a clearer understanding of the numerous processes involved within the cancer early detection period. The accrual of information and knowledge was valued and found to support a sense of independence and control, providing reassurance with the perceived ability to cope better. Participants used coping as a mechanism to adapt to the threat of illness, which helped to alleviate some of the anxiety experienced. The findings around coping mechanisms corroborate with the transactional theory of stress and coping (Lazarus, 1999; Lazarus & Folkman, 1984) with problem-focused and emotion-focused coping as the two main strategies used. The strategies ranged and gave several benefits including; feelings of being more in control (through planning); a release of emotions (crying); purpose and status (distraction); the ability to break it into manageable stages (compartmentalising), and; a lightening of perceived burden (humour); anxiety relief (accruing information and knowledge).

Participants acknowledged that their own expectations of what ‘being a man’ constituted, and their perceived expectations of others, impacted on their experience of the period. Issues of disclosure and protection of others were central to the link between communication tension, issues of masculinity and the impact on men’s experiences during the cancer early detection period. Effective communications with HCPs included factual and to-the point dialogue, resulting in an improved sense of control and increased confidence.

Strengths and Limitations

The critical realist approach taken, using data-driven inductive thematic analysis (Braun and Clarke, 2006) enabled the holistic experience of participants to be captured fully. The valuable contribution that the findings make to the small body of research within the cancer early detection field with men is also beneficial. In relation to the sample demographics, there were both identified strengths and weaknesses.

The researcher’s role and position is central to the research process and can impact upon the interpretation of the methods, concepts and analysis of findings (Demery et al., 2012), particularly within qualitative studies (Jootun, McGhee, & Marland, 2009; Mays & Pope, 2000; Murphy et al., 1998). The researcher is female in gender and believes that this may have had an influence upon participants’ responses. Participants talked about sensitive issues, and may not have been as open if they felt that they had to conform to masculine traits of stoicism and suppression of emotions if the researcher was male. The networks and existing relationships within the sector helped with the recruitment process, and as several of the participants had met the researcher before (during events related to her occupation), a certain element of rapport was already built. It is believed that this supported an element of trust which aided the flow of information.

Another strength was the range of men with different sexual orientations, with over 10% of the cohort defining themselves as gay. However, despite some purposive sampling towards the end of the study, most of the cohort consisted of individuals who were White British and thus not necessarily representative of men undergoing testing within the general public. Previous research has demonstrated that men from Black Asian Minority Ethnic (BAME) communities experience cultural issues in relation to cancer screening (Johal, Shelupanov, & Norman, 2012) and encounter stigma when seeking help (Wilkins, 2013), with more fatalistic attitudes towards cancer. This study was therefore unable to explore these issues due to the minimal BAME sample included. However, the aim of this research was to understand from men who have been through the testing period, with the main interest in prioritising the psychosocial needs identified which was achieved.

The study was retrospective in nature. Although this may be viewed as a limitation in terms of accuracy and recall of information, the benefit of the approach enabled the recruitment of a mixed cohort (in terms of the experiences of participants) with differing diagnostic outcomes. Finally, the sample was self-selected and those who agreed to be involved may have had a particular interest in the study, which might have limited the findings. The majority of participants identified their ethnic group as White British, and therefore men from BAME (Black African Minority Ethnic) were not fully represented. Future research should consider working with community organisations who have effective networks within BAME communities to support communications, outreach and engagement of participants.

Telephone interviews were chosen as they extend access to participants, due to the asynchronous communication of place, compared to face-to-face interviews (Opdenakker, 2006). This enables access to participants who may be deemed harder to reach or work with on a face-to-face basis. Therefore, using the telephone may have resulted in participants being less prohibitive in discussing their experiences, as other studies on sensitive matters have found (Greenfield, Midanik, & Rogers, 2000; Sturges & Hanrahan, 2004; Trier-Bieniek, 2012). However, one limitation with telephone interviews is that they prevent the researcher from observing visual cues and prohibit the ability to observe the body language of the participants, which may have provided further information (Opdenakker, 2006).

Implications for policy, research and practice

Several unmet needs were related within the sub-themes identified and provide evidence of the need for information and support. These related to the easy accessibility of credible, quality resources and information on wider holistic issues, not just those which are biomedical ‘procedural’ focused. There was an additional unmet need around being able to have timely access to other male peers, who have been through the cancer early detection period, as the value of hearing other men’s experiences enabled normalisation of their own thoughts and emotions in addition to also managing their expectations about the next steps. This unmet need is particularly important for future isolated men who may not have a wider social support network to rely on. In line with the ‘valued identity as a man’ and issues of masculinity, participants wanted to be independent in coping and managing during the period but reported unmet needs around access to emotion focused coping strategies. Lastly, some unmet needs related to developing skills to enhance communication and build knowledge of how to navigate the ‘system’.

In relation to the findings, participants highlight that seeking help and support is impacted by issues of masculinity, during the cancer early detection period. The need to protect others and a desire to be independent and not burdensome caused some participants difficulties and distress. Recent studies have shown that the acceptability of self-management support interventions targeting men can be enhanced when the context, content, and delivery style is bespoke to the valued aspects of male identities (Galdas et al., 2014; Hunt et al., 2013; Hunt et al., 2014a; Hunt et al., 2014b; Robertson et al., 2014). Therefore, any future information, resources, support or intervention designed to support men during the early stages of cancer detection needs to ensure that it is aligned with these values.

The desire to hear from others and the need for social connection aligns with Galdas et al.’s (2014) systematic review which identified the value men place on hearing the lived experiences of peers and being acknowledged as experts by experience. These findings are pertinent given the suggestion that when men feel vulnerable they experience more intense emotions than they are used to feeling, with an increased need for emotional support (Gray et al., 2000). This highlights the importance of emotional support and resources during the period and the additional need for alignment of support. This study adds weight to the argument that men want support to address their holistic needs during the cancer early detection period. However, the support must be facilitated in a way that takes into account their needs as a man, for independence and self-reliance, and is accessible in a way that enables them to keep their valued identity, to not have to disclose if they choose not to.

These findings add to the case to provide support, addressing the holistic needs of men, using accessible mediums that men use. Online evidence-based information and support offers men an option that fits with their need for anonymity and flexibility to access support at an appropriate time. Recent studies have found web-based interventions to be promising mechanisms to deliver education and information to meet the needs of people affected by cancer (Lubberding et al., 2015; Ventura, Öhlén, & Koinberg, 2013; Wheelock et al., 2015; Wolpin et al., 2014).

Only limited research has focused on the cancer early detection period, as most of the research identifying the needs of patients has examined the treatment and post treatment phases (Wiljer et al, 2012, 2013). NICE (2015) guidelines for suspected cancer recognition and referral highlight the lack of information on both patient information needs and patient experience throughout the cancer diagnostic pathway. It recognises that filling the gap should improve future patient experience and calls for more qualitative studies to be published to highlight the need to assess the key issues in patient experience and information needs in the cancer diagnostic pathway. In line with this study and the NICE (2015) guidelines, this study offers a valuable contribution to the cancer early detection research field and forms a basis for further research into patient satisfaction, quality of life and patient perception of the quality of care and information. Recognised within the limitations of this study, men from BAME communities experience issues (related to culture) in the cancer early detection period and therefore it is important that studies include explicit information about the sample regarding ethnicity. Further studies targeting men from BAME communities are needed.

Conclusion

This qualitative, interview-based study has identified a broad range of psychosocial needs and requirements, in relation to experiences, of men during the cancer early detection period. The study highlights how the extent and intensity of men's needs vary from individual to individual and are influenced by several factors, with consensus of unmet needs and requirements relating to reassuring care; access to credible information; and emotional support. The experiences of the period are influenced by a multitude of factors, including: having access to a supportive individual; their access to a social support network; tailored information; the effective use of positive coping mechanisms (such as planning, distraction, crying, humour), and; confidence to communicate effectively.

Men wanted to be able to know where to gain credible information, how to connect and learn from other men's experiences, and support to manage the emotional impact of the period. Future interventions to support men to manage - emotionally and socially - during the cancer early detection period (with its associated distress and uncertainty) may benefit by providing connectivity with other men's experiences to bring a sense of meaning, shared information and encourage positive coping strategies to address and self-manage effectively during the period. This study has highlighted an opportunity to explore the development of resources (readily accessible to men, delivered in a meaningful way) that enable men to unburden themselves confidentially without burdening others, whilst preserving their need for independence and self-reliance. Resources, or an intervention that could adopt a targeted approach, has the potential to reap benefits for the individual and for healthcare professionals who have limited time and resources. There is a current lack of evidence, particularly qualitative studies, assessing the key issues in patient experience and information needs in the cancer diagnostic pathway (NICE, 2015). The findings from this study have the potential to provide key insight that may be of national significance for what information and support is needed, and has the potential to improve future patient experience (NICE, 2015). However, it is not clear what the highest priorities of need are for men during the cancer early detection period. Therefore, the next chapter will look to fill this gap in understanding, by conducting a study to prioritise the order of needs identified.

Chapter 4 – Identifying the prioritised needs of men during the cancer early detection period – a modified nominal group technique study

Introduction

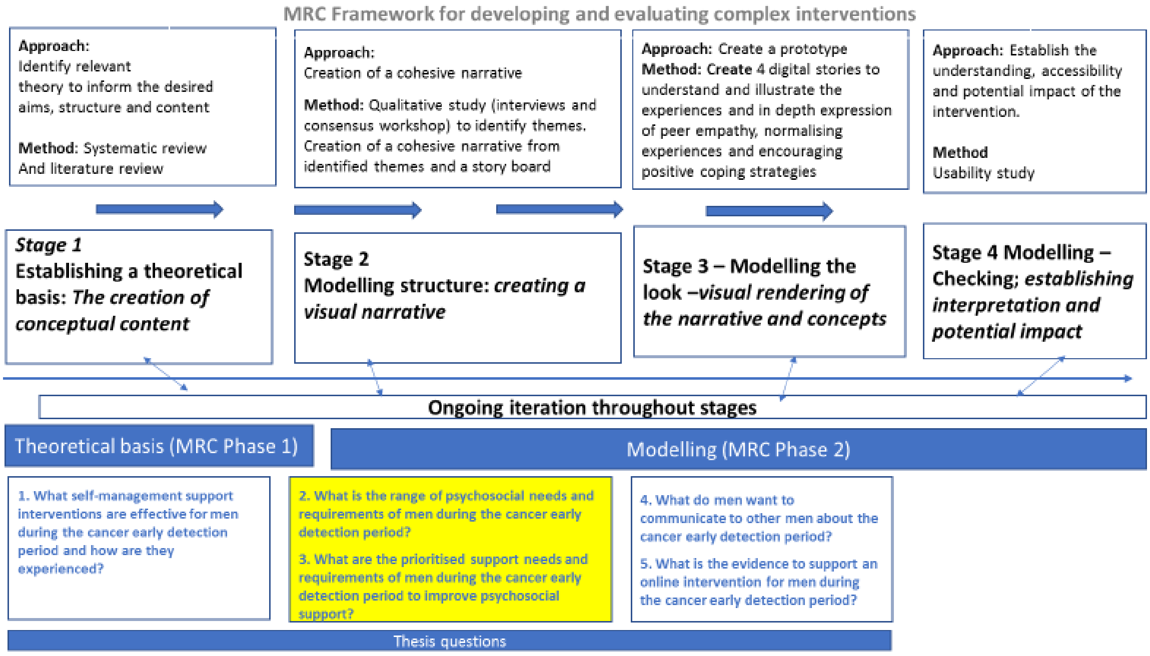
As outlined in the previous chapter, an indepth interview study with men who had experienced the cancer early detection period, a range of factors influence both the individuality of experiences and the commonalities of needs each man encounters. Although the range of needs and experiences varied across the accounts, there were many common, central needs identified, including: the accessibility of social support and tailored information; the use of coping strategies; and; communications with healthcare professionals. The study created an understanding of men's experiences and needs during the cancer early detection period, concluding with the need to gain consensus and prioritisation of the identifed needs. There were a number of key design considerations when reviewing the potential methods for the prioritisation process. A key consideration was the opportunity to explore participants' interpretations and understanding - thus acknowledging the influences that can impact upon it - in line with the critical realism approach (Bhaskar, 2010; Maxwell & Mittapalli, 2010; Scott, 2007). The overall design needed to: provide active participation of all group members; gain a consensus view within a short duration; and provide feedback and satisfaction to contributors. Therefore, taking all considerations into account, a Nominal Group Technique (NGT) approach was chosen for this study as it has the advantage of being particularly helpful where not much is known on the topic and participants have differing views (Murphy et al., 1998), allowing all participants to raise points in a protected format (whilst prohibiting rejection of other participants) (Wellings, Branigan, & Mitchell, 2000).

The cancer early detection period includes a process of events that men work through (initiated by cancer screening or diagnostic tests, for those who have symptoms), leading up to obtaining diagnostic confirmation. The period can be emotionally challenging due to the imminent threat of a cancer diagnosis, which can create anxiety (Saegrov & Halding, 2004) and impact on psychological wellbeing (McQueen, 2009). Understanding what needs men have during the cancer early detection period creates an opportunity to build knowledge and explore how those needs might be optimally supported and prioritised. The ability to prioritise support needs enables the effective allocation of resources for improving quality of service provision (Bonovski et al., 2000; Gustafson et al., 1993; Gustafson et al., 2003).

With rising cancer incidence rates (Smittenaar et al., 2016), there is a pressing need to extend the limited current knowledge of the highest prioritised needs of men during the cancer early detection period. Aligned with the critical realism approach, there is recognition of the importance of subjectivity, along with objectivity, to extend knowledge of the needs of men during the cancer early detection period, as greater patient satisfaction is associated with better cancer outcomes (including better engagement with health services and healthcare professionals) (Brédart et al., 1998; Gesell & Gregory, 2004; Sandoval et al., 2006a, 2006b; Skarstein et al., 2002; Wiggers et al., 1990).

As detailed earlier in Chapter 1, the UK Medical Research Council Framework for the Development and Evaluation of Complex Interventions (Craig et al., 2008) provides the structure for each of the chapters. This study seeks to explain the process of applying Phase 2, Stage 2 (Modelling structure – creating a visual narrative) of the Framework specifically to identify the prioritised needs of men during the cancer early detection period to aid the construction of a narrative for the intervention (refer to Figure 8).

Figure 8 – MRC Framework Phase 2 - Stage 2



Aim

The aim of the study is to understand the priority of identified needs for men who have been through testing for cancer and will answer this research question:

What are the prioritised support needs and requirements of men during the cancer early detection period to improve psychosocial issues?

Method

The NGT facilitates efficient group decision making in social psychological research (Delbecq & van de Ven, 1971) and has been used successfully in various areas of health research (Campbell & Cantrill, 2001; Telford et al., 2004). Used to identify priorities within cancer research and services (Boberg et al, 2003; Corner et al., 2007; Luboldt et al., 2004), the systematic stages of the NGT method (Potter, Gordon, & Hamer, 2004) facilitate a participatory approach (Bruce et al., 2002) to ensure effective prioritisation of needs (Coker, Tucker, & Estrada, 2013; de Ruyter, 2010) and group consensus (Harvey & Holmes, 2012).

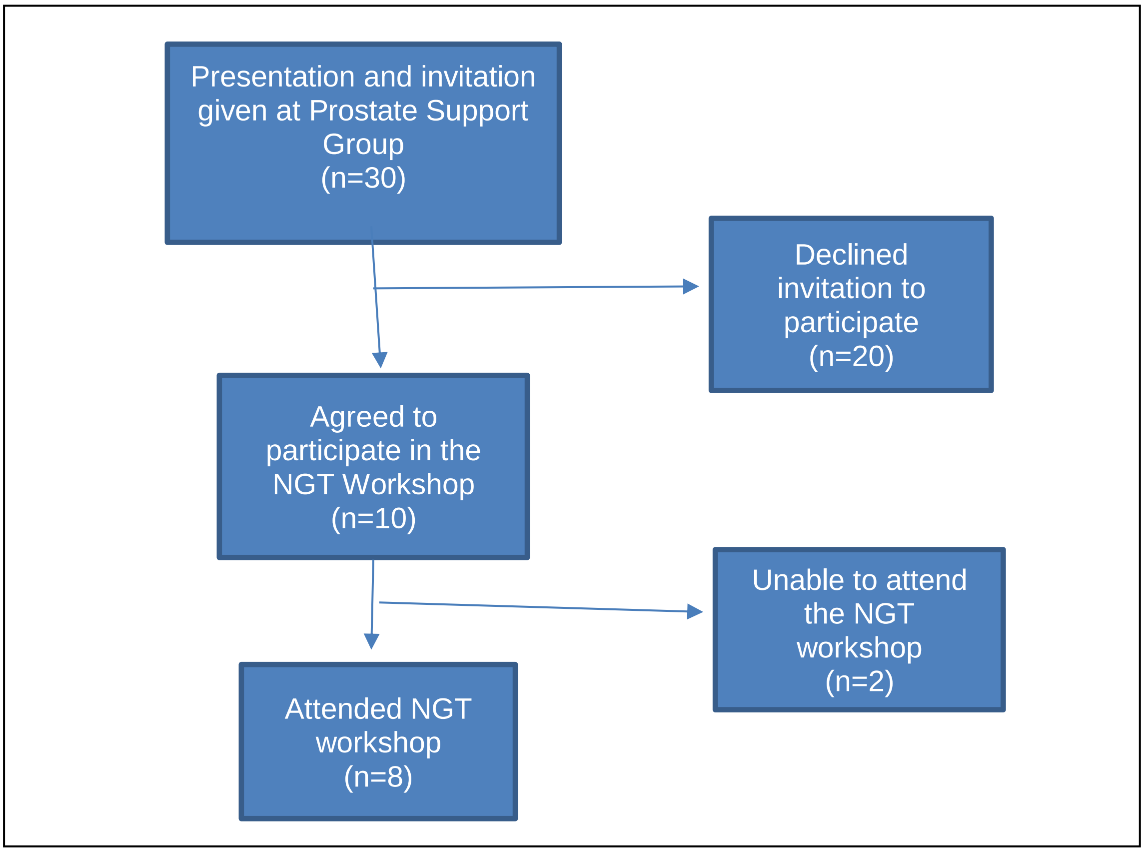
The approach was chosen for this study as it has the advantage of being particularly helpful where not much is known on the topic and participants have differing views (Murphy et al., 1998), allowing all participants to raise points in a protected format (and so prohibits rejection of other participants) (Wellings et al., 2000). The structured format promotes the active participation of all group members, and equally weights the votes of each participant to gain a consensus view. Potter, Gordon and Hamer (2004) highlight that the ability to gain consensus within a short duration, and the immediate feedback and satisfaction it offers to contributors (Potter, Gordon, & Hamer, 2004; Twible, 1992), are advantageous over other methods such as Delphi (Delbecq, van de Ven, & Gustafson, 1975), brainstorming and focus groups (Stewart & Shamdasani, 1990).

The purpose of the NGT developed by Delbecq, Van de Ven and Gustafson (1975) is to make groups more democratic, efficient and effective. A typical NGT meeting involves 6-15 people seated around a table with a leader. The limited numbers within the group enhances the opportunity to talk more openly about sensitive topics (Braun & Clarke, 2013; Liamputtong, 2009). The standard first step, when using NGT, is to ask participants to do preparatory work by identifying related topics and ranking them prior to attending the workshop (Aspinal et al., 2006; Fox, 1989; Redman et al., 1997). The group session would then be used to present, discuss and exclude certain items. Participants would be invited to re-rank the revised issues (Andersen & Fagerhaug, 2000; Aspinal et al., 2006). However, other studies prioritising sensitive issues have used a modified approach to limit prior preparation (Aspinal et al., 2006). Given the sensitive topic, a modified version was also considered to be appropriate for this study due to the sensitive topic and issues with engaging men in groups. This approach was taken for the purposes of this study for several reasons. It is recognised that researchers undertaking enquiries on sensitive subjects are in a unique position to be able to use a range of methods to create a platform for participants to tell of their experiences. However, both the physical and emotional risks need to be considered carefully (Dickson-Swift et al., 2008). When discussing sensitive topics with participants, and asking them to recall issues that may be deeply personal (Dickson-Swift et al., 2009; Lee, 1993), there are ethical considerations and risks that need to be taken into account with the process and method for data collection (Dickson-Swift et al., 2008).Corbin and Morse (2003) highlight the potential for individuals to experience powerful emotions and grief when discussing sensitive topics and identify that the ultimate responsibility for protecting the rights of participants, lies – not with ethics committees – but with researchers. Therefore, researchers are responsible for pre-empting, managing and mitigating potential risks. There is also a responsibility of the researchers to create a comfortable climate, and develop a trusting researcher–participant partnership where participants feel relaxed and uninhibited (Polkinghorne, 2005). Taking these factors into account, it was felt that participants may have been adversely affected if they saw individual statements of importance extracted and discarded by the group. Therefore, each participant received the ‘identified needs’ at the workshop and independently, in secret, gave each statement a score, attempting to minimise potential discomfort or distress. It was also identified that asking participants to undertake preparation may prevent attendance at the nominal group workshop. The NGT was, therefore, modified to improve the experience for participants and minimise potential discomfort or distress. In place of this, the 25 themes of identified needs (generated from the previous qualitative study as outlined in Chapter 3) were presented to the group to reflect on and prioritise.

Participants

As the items were generated by the previous qualitative study (the sub-themes from Chapter 3), it was important to have a new group of participants (from those who had been involved in the previous study) to prioritise the identified items objectively. As the previous study included men who had been through testing, from a wide range of cancer types, the aim of this study was for men to prioritise the items, irrespective of the cancer type they had been tested for. However, as men are more likely to be diagnosed with prostate cancer than other cancers – and develop distress or psychological problems (Bill-Axelson et al., 2011; Ferlay et al., 2015) – recruitment was concentrated on men who had been through testing for prostate cancer. Recruitment for participants used convenience sampling and commenced in April 2017 with a presentation about the study to members of a Midlands-based prostate support group. Recruitment for participants used convenience sampling and commenced in April 2017 with a presentation about the study to members of a Midlands-based prostate support group. As illustrated in the flowchart (Figure 9) of study participant recruitment 20 men declined to be involved in the study following the presentation to the support group, their reasons for declining were not collected. The study inclusion criteria included being over 18 years old, having had a confirmed cancer diagnosis and English speaking. Figure 9 illustrates the detail and stages of the recruitment.

Figure 9 - Flowchart of study participant recruitment



Once an overview of the study had been given, further information was distributed and interested participants were encouraged to make contact with the researcher via email or telephone to register their interest in being involved in the consensus workshop (Appendix 11) and were given an opportunity to ask questions prior to the study's commencement. Once participants registered an interest, they received an information sheet (Appendix 12) and consent form (Appendix 13) to sign and send back to the researcher in a self-addressed pre-paid envelope. Once sufficient participants had been recruited (more than six people) to meet the requirements of a productive NGT group (Delbecq & van de Ven, 1971), a mutually agreeable date was arranged.

Procedure

Participants were asked to read the participant information sheet (Appendix 12) and subsequently invited to participate in a face-to-face workshop. The researcher successfully gained funding through the Supporting Postgraduate Students in Industry for Employability in Research (SPIDER) placement funding at Coventry University to be able to fund a comfortable venue. The researcher sourced a community venue that was near to where participants lived and known to the group, and through community contacts obtained the football executive box overlooking the pitch. The attraction of the venue and the offer of a light supper were viewed as important by the researcher to ensure that participants felt looked after and were comfortable. To meet Coventry University guidelines for studies undertaken by students, an ethics application was submitted, and approval granted by the Health and Life Sciences (HLS) Ethical Committee ID: P50660. As participants were recruited directly via support groups and community groups, NHS ethics approval was not required, as recruitment was not via healthcare professionals or a healthcare provider.

The stages of the workshop follow a modified version of the NGT protocol designed by Potter, Gordon and Hamer (2004) (full detail of the stages of the workshop are included in Appendix 14). During the introduction to the workshop, participants were reminded that they could withdraw from the study if they wanted to, and the purpose and procedure of the meeting was explained by the researcher. Participants were invited to ask questions throughout and to stop the researcher if needed at any time. Participants gave consent for the workshop to be recorded by Dictaphone. The 25 themes of identified needs (generated in Chapter 3) were presented on a sheet and a flipchart. Participants were invited to seek verbal explanation about the items, and the researcher took time to guide the facilitation without spending too long on a single item. The group had opportunity to suggest new items for discussion, but no needs were eliminated. Participants were asked to select the statements that were most important to their wellbeing, and rank these in priority order individually (starting with ‘1’ as the highest prioritised need and so on).

The participants were invited to vote and rank the recorded needs in relation to the original question. The participants were asked to, independently, allocate weighting scores based on their perceptions of their needs. Each participant was given a sheet of number coloured dots and ranked the identified needs in priority order, independently (on their own), starting with 1 as the highest priority and 2 as the second and so on. The researcher then totalled up the scores and presented them on the flipchart, so participants could visually see the immediate results in response to the question, and the meeting concluded having reached a specific outcome. The NGT workshop lasted a total of 110 minutes in total.

Analysis

In line with the critical realism approach, it is acknowledged that there will be different interpretations, and that factors including the analysis of findings from empirical studies will affect the generation of knowledge (Maxwell & Mittapalli, 2010). The study’s objective was to compile a ranking of priorities of need through applying a nominal group technique. This produced two forms of data: a prioritised list of items arranged by participants, and a transcript of workshop discussion. The workshop transcripts detailed participants’ reasons for identifying the needs that were important to them, and the meaning of the needs. To develop a complete list of themes, inductive data-driven thematic analysis grouped similar topics (Braun & Clarke, 2006).

Qualitative analysis

The discussions from the workshop were transcribed verbatim, anonymised and collated using NVivo 11 by the researcher. The workshop transcript was analysed using inductive data-driven thematic analysis (Braun & Clarke, 2006). Thematic analysis is a useful method to identify themes within the data and the analysis followed the six-phase process by critical reflection (see Appendix 6) (Braun & Clarke, 2006). The workshop transcript was read twice individually and examined in depth and notes were made. Initial coding was applied with the purpose of being open to many interpretations. The codes applied represented the participant’s experience or thoughts and, where possible, links were made between identified needs. Development included the constant review of the incorporated areas of interest from the workshop schedule, which led to new, emerging codes. Once coding was complete, focus was given to identifying the themes. The identification of themes was an iterative process which enabled the development and emergence of themes, the highest level of coding. The codes and themes were organised using NVivo 11 software. The scripts and identified themes were reviewed independently by another experienced researcher in the supervision team. Following the coding, and application to a theme, a visual map was created to illustrate the themes and coding outline (included in Fig.10). The creation of the visual map aided the understanding of the connections within the data.

Irrelevant text has been omitted from the quotes and replaced with an ellipsis ('[…]'). Square brackets are used to clarify topics of discussion. Participants' codes (P) are included at the end of each quote to easily identify who it relates to.

Quantitative analysis

The participant's quantitative scoring involved ranking item importance from the most important to the least important (Delbecq & van de Ven, 1971; Delbecq, van de Ven & Gustafson, 1975). The importance scores for each identified need were calculated using the individual participant's rankings. The highest ranked factor for each participant was given 1 point, the next 2 points and so on until the least important factor was given the most points. The prioritisation scores were calculated using the mean, and the top factors (with the lowest mean scores) were identified in priority order (the lower the mean score, the higher the priority). The participants ranked prioritised list of their needs and through open dialogue they were provided with the space to discuss the strength of the statement (Lloyd-Jones, Fowell, & Bligh, 1999; MacPhail 2001). The quantitative findings provided a baseline for a qualitative analysis of the priorities participants determined to be their highest needs.

Results

Eight participants who had been through the cancer early detection period were recruited. The sample size, and its homogeneity, are compatible with the NGT (Delbecq & van de Ven, 1971), with optimum participants to gain a constructive approach. The participants' ages ranged from 65 to 75 years old (with an average age of 68 years old). The time since diagnosis ranged from 7 to 50 months (with an average of 24 months). Seven participants were married, and one was cohabiting (refer to Table 12). All participants identified their sexuality as heterosexual and were White British.

Table 12 – Demographics of Participants

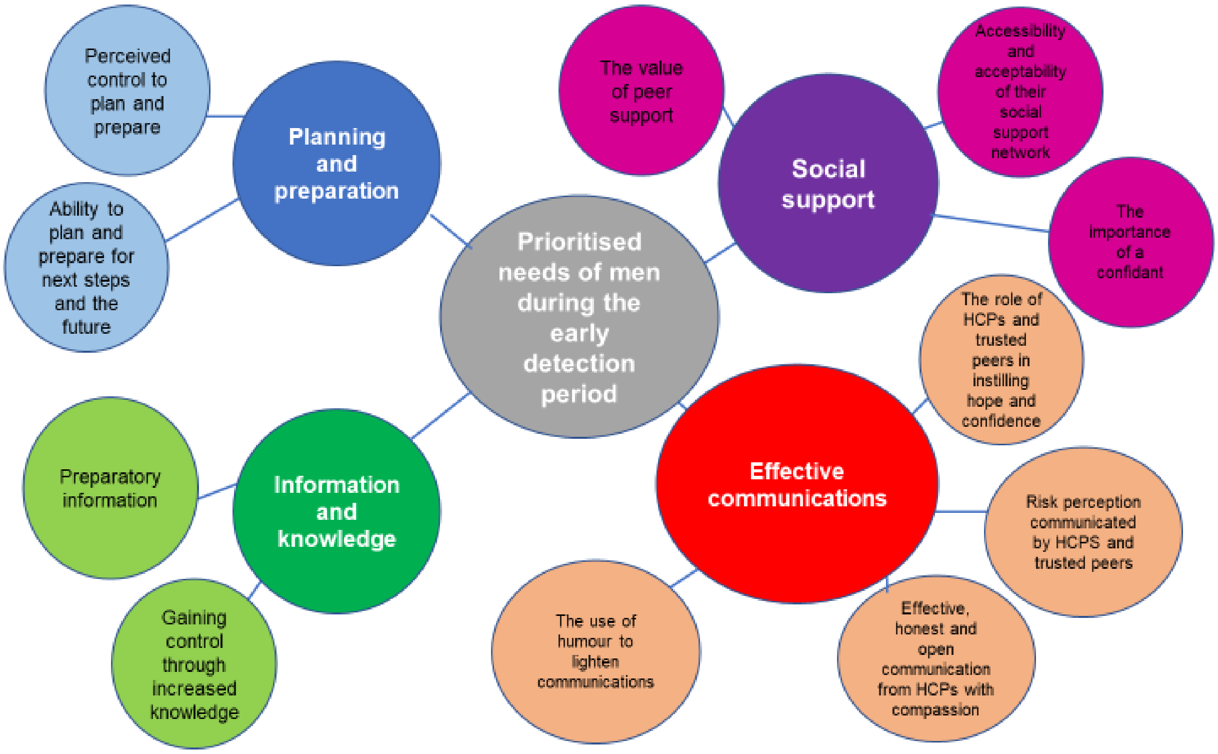
		Study Participants
Age at interview	Mean	68 years
	Range	65 - 75 years
Relationship Status	Married	7
	Cohabiting	1
Sexual orientation	Heterosexual	8
Time since diagnosis	Mean	24 months
	Range	7- 50 months

Twenty-five themes of identified needs were previously generated from the qualitative study conducted as outlined in Chapter 3 (see Appendix 15). Appendix 16 illustrates each of the identified needs with extracts from the transcripts.

Findings

Four prioritised themes were identified by participants: (1) Planning and preparation; (2) Effective communications with HCPs; (3) Social support; and (4) Information and knowledge (Figure 10).

Figure 10 - A map of prioritised themes related to the needs of men during the cancer early detection period.



Theme 1 - Planning and preparation was the highest rated theme. This included the specific needs of: perceived control to plan and prepare (MS 3.25), and the ability to plan for next steps and the future (much wider than health) (MS 2.7). This included the practical planning of aspects such as the ability to think through potential next steps of how to tell family members (if a diagnosis was confirmed) and considering potential options for work arrangements (and other commitments). The ability to start action-orientated problem solving was felt to be valuable. Participants illustrated how unprepared they felt when this need wasn't met as "*I just felt that I wanted to know what the options were"* (P5), highlighting the brevity of decision making with little decision-making support:

> "*you've just been told you've got Prostate Cancer and basically within 30 seconds you're expected to make a decision […] what treatment do you want […] it was something that I absolutely knew nothing about."* (P3)

Theme 2 - Effective communication was the second highest prioritised theme for participants. The identified needs associated with effective communication with healthcare professionals were: compassionate, open and honest exchanges of communication (MS 2.1); the way in which risk perception is communicated (MS 2.5), and; the need to use humour to lighten communications (MS 5.75). Through reflecting on poor communication experiences with healthcare professionals, such as being told *"everybody's gotta die some time"* (P3), participants prioritised effective communication in recognition of needing "*somebody more sympathetic"* (P11). The role of HCPs in instilling hope and confidence was valued especially by participants (MS 5.1). Participants rated the need to lighten the face-to-face consultations (MS 5.75) and talked about how humour helped them deal with consultations. One participant talked fondly of his consultant's use of humour: *"a grand chap"* who he was able to "*have a laugh with"* (P6).

Theme 3 - Social support was the third highest prioritised theme. The factors of need included: having at least one supportive individual to talk to (MS 2.3); the accessibility and acceptability of their social support network (MS 4.4), and; the value of a peer group (and the experiences of others) (MS 5.9). Participants rated the need for a supportive individual as a high priority (MS 2.3). The accessibility and acceptability of their social support network (MS 4.4) was justified by highlighting the importance of others' experiences in enabling additional information and support to be sought. Support of peers was also important (MS 5.9) and participants spoke about wanting to talk to men who had been through the experience to gain support, but accessing them was an issue as "*there was nobody else I knew to talk to"* (P5).

Theme 4 - Information and knowledge was the fourth highest prioritised theme. Participants rated: the need for control linked to accruing knowledge (MS 4.5), and preparatory information-seeking that supports the next stage (MS 4.8). The need to be informed to be able make decisions was highlighted as important:

> *"Between the DRE [digital rectal examination] and going back to being told and all that kind of stuff I spent a lot of time going through and reading up on just about everything I could and so I think I was fairly well prepared […] so when she told me what my score was it was ok for me it wasn't that stressful because I knew what the outcome for me could be."* (P5)

Taking into account the mean scores of the needs relating to the well-being items and the mean scores of the wider needs provided a prioritisation of the four overarching themes. This was based on the top highest item scores given by participants (across well-being needs and wider needs), when the weighting of each factor was taken into consideration (see Table 13).

Table 13 – Top prioritised themes

Theme number	**Main theme**	**Theme**	**Mean score**	**Score**
1	Planning and preparation	Perceived control to plan and prepare	3.25	2.97
		Ability to plan and prepare for next steps and the future (much wider than health)	2.7	
2	Effective communication	Effective, honest and open communication from Healthcare Professionals (upfront and to the point) with compassion	2.1	3.86
		Risk perception communicated by HCPS and trusted others	2.5	
		The role of HCPs and trusted others in instilling hope and confidence	5.1	
		The use of humour to lighten communications	5.75	
3	Social support	Having at least one 'supportive individual' to talk to	2.3	4.20
		Accessibility and acceptability of their social support network	4.4	
		The value of peer support (and the lived experiences of others who had experience of cancer)	5.9	
4	Information and knowledge	Gaining control through increased knowledge	4.5	4.65
		Preparatory information seeking (supports the next stage)	4.8	

Most important needs during the cancer early detection period

As shown in Table 14 the most important factor was the effective, honest and open communication from Healthcare Professionals (MS 1.4). The second most important factor was to be able to plan and prepare for next steps and (MS 2.7).

Table 14 - Top identified needs with importance scores

Identified needs	Rank	Ranked importance score (mean)
Effective, honest and open communication from Healthcare Professionals (upfront and to the point) with compassion	1	1.4
Ability to plan and prepare for next steps and the future (much wider than health)	2	2.7
Gaining control through increased knowledge	3	4.5
Preparatory information seeking (supports the next stage)	4	4.8
The role of HCPs and trusted others in instilling hope and confidence	5	5.1
The use of humour to lighten communications	6	5.8
The value of peer support (and the lived experiences of others who had experience of cancer)	7	5.9
Dealing with uncertainty	8	6.3
Dealing with anxiety, shock and disbelief	9	6.4
Importance of individuality and person-centred support	10	6.8

Most important needs that contributed to wellbeing during the cancer early detection period

As shown in Table 15 participants choose the items – from the 25 items presented – that contributed to their wellbeing during the cancer early detection period and rated the most important needs. The highest needs related to ‘having at least one supportive individual to talk to’ and the same mean importance score was given to ‘risk perception communicated by healthcare professionals’ (MS 2.25) with ‘risk perception communicated by healthcare professionals’ (MS 2.5). This was subsequently followed closely by the perceived control to plan and prepare, with the mean score of 3.25. These needs were followed in order by the need for: gaining knowledge through credible information sources; accessibility and acceptability of social support network, and; having an outlet for releasing anxiety and worry.

Table 15 - Needs that contributed to wellbeing during the cancer early detection period

Top identified needs		Ranked importance score (mean)
1	Having at least one supportive individual	2.25
2	Risk perception communicated by healthcare professionals and trusted others	2.5
3	Perceived control to plan and prepare	3.25
4	Accessibility and acceptability of social support network	4.3
5	Gaining knowledge through credible information sources	4
6	Having an outlet for releasing anxiety and worry	4.6

Discussion

The aim of the study was to understand the priority of needs of men in relation to the cancer early detection period. The findings generated four themes, building insight and understanding of the core concepts of men's priority of identified needs in relation to the cancer early detection period.

Relating findings to literature

Men want to feel in control, by being able to plan and prepare, and report how being able to focus on this supports their coping whilst they navigate the uncertainty of the period. The highest rating of 'planning and preparation' is consistent with the action-orientated, clear purpose approach that has found to be appealing to men, in line with a preference for problem-focused coping (Adamsen, Rasmussen, & Pedersen, 2001; Barlow, Edwards, & Turner, 2009a; Barlow, Turner, & Gilchrist, 2009b; Bell et al., 2010; Bourke et al., 2012; Dickerson et al., 2011; Gray et al., 1996; Oliffe et al., 2010; Seale, 2006; Sullivan, 2003; Seymore-Smith, 2008). Planning and preparation give men a sense of control that, evidence suggests, can affect beliefs about their ability to cope (as recognised with several different conditions including cancer) (Bare`z et al., 2007, 2009; Bremer et al., 1997; Henselmans et al., 2009a; Tennen & Affleck, 2000). Research has demonstrated that coping strategies strongly predict an individual's quality of life more than medical factors in relation to cancer (e.g. Avis, Crawford, & Manuel, 2005; Lehto, Ojanen, & Kellokumpu-Lehtinen, 2005). Therefore, the ability to plan and prepare – by developing insight and information about the next steps – has the potential to buffer against stress (Helgeson, 1992, 1999; Henselmans et al., 2009b; Penninx et al., 1996).

Participants gave a high rating to planning for next steps. This corroborates with findings that interventions focused on instrumenting change and control can be more acceptable to men (Galdas et al., 2014), in line with traditional masculine ideals (Corboy, McDonald and McLaren, 2011). Other work in the area of gender difference in cancer patients' needs report that women are more inclined to look for emotional support, whereas men are more inclined to seek ways to enhance their knowledge (Dale et al., 2004; Klemm et al., 1999; Sharf, 1997). Participants valued effective communication exchanges with healthcare professionals during consultations. Value was placed on honest and open dialogue with healthcare professionals, delivered with compassion and the appropriate use of humour. This finding is important because involving men within clinical encounters has the potential to impact on increased satisfaction through working in partnership and a sense of balanced power (Bourke et al., 2012; Corboy, McDonald, & McLaren, 2011). Men gain value from the opportunity to interact with professionals and ask questions (Arrington, Grant, & Vanderford, 2005; Bourke et al., 2012; Oliffe, 2005; Sullivan, 2003) as communication between patients, partners and HCPs is a multidimensional dynamic process (Baile, Aaron, & Parker, 2009) including both factual and affective components. For example, the components may include both the receipt of factual information about potential future treatment decisions, in addition to the confirmation and normalisation of experiencing emotions, such as anxiety provoked by the uncertainty. This highlights the important role HCPs have in facilitating consultations during the cancer early detection period. This finding suggests that there is as much a need for a compassionate inclusive approach (that is empathic), during the detection period, as there is at other stages of the cancer trajectory (Carter et al., 2011; Ervik, Nordoy, & Asplund, 2010; Galbraith, Hays, & Tanner, 2012; Milne, Spiers, & Moore, 2008; O'Brien et al., 2010, 2011; Ream et al., 2009; Thomas, 2013; Walsh & Hegarty, 2010). The impact of effective communication and increased involvement in consultations is improved clinical encounters, which have the potential to lead to improved satisfaction and better outcomes (Bourke et al., 2012; Corboy, McDonald & McLaren, 2011).

Participants in this study also prioritised the need to have access to social support from a supportive individual, and from peers who have been through the cancer early detection period. This is important because social support – from a supportive individual and/or peers – impacts on social connectivity and influences the adoption of coping strategies (Naslund et al., 2015; Newhouse, Atherton, & Ziebland, 2017; Ziebland & Wyke, 2012). This has the potential to provide multiple benefits, including: a sense of empowerment to be able make informed decisions (Entwistle et al., 2011); a reduction in isolation, and;

giving confidence by managing expectations (Lowe et al., 2009). Being identified as part of a group has been found to reduce uncertainty and build self-efficacy (Brewer, 1991; McKenna & Bargh, 1998), providing a shared sense of belonging. Peer support, sharing experiences with other men is empowering and provides a sense of meaning in men's experience of cancer (Galbraith, Hays, & Tanner, 2012; King et al., 2015) even when the information provided is not positive (Krumwiede & Krumwiede, 2012). Through shared experience, a sense of hope is instilled, reducing feelings of isolation, and increasing knowledge about the experience and consequently increased awareness of potential coping strategies (Legg et al., 2011; Moulton et al., 2013; Ussher et al., 2006). Even if men have maladaptive coping strategies (Ptacek, Pierce, & Ptacek, 2002), the support from a partner has been found to be beneficial to men’s quality of life (Green, Wells, & Laakso, 2011; McCaughan et al., 2013; Movsas & Scott, 2006;) compared with unpartnered men (Kongrad et al., 1996).

The last theme encompasses the building of information and knowledge to manage thoughts, feelings and keep control. These findings corroborate with the research of O'Shaughnessy et al*.* (2013a), that at initial diagnosis men's anxiety and psychological support needs are heightened. The process of accruing factual information has been shown to impact on and increase feelings of control (Arrington, Grant, & Vanderford, 2005). The cancer early detection period is an opportunity to address men’s holistic needs. If unmet needs are left undealt with, they will have a psychological impact later in the cancer journey (Chapman, 2005). Although men acknowledge a need for support, women are more inclined to articulate their psychosocial needs (Keller and Henrich, 1999).

Studies have found that it is important for men to be able to express their holistic needs in a way that fits with their culturally valued masculine ideals (Corboy, McDonald, & McLaren, 2011). This study has highlighted important implications for further work around understanding needs, as the long-term need for emotional and psychological support continues through treatment and into survivorship (Ervik, Nordoy, & Asplund, 2010; Galbraith, Hays, & Tanner, 2012; O'Brien et al., 2010; Oliffe et al*.,* 2009; O'Shaughnessy et al., 2013a; Ream et al*.,* 2009; Thomas, 2013). The findings suggest some support for the concept that the threat of a suspected cancer diagnosis, waiting for the results, and confirmation generates a range of needs. It could be argued that the time between testing and diagnostic confirmation presents an opportunity for framing support in a way which calibrates with men’s needs and their ideals.

Men who have been through testing for cancer have clear views on the important priorities to be addressed during the cancer early detection period. The findings suggest that the experiences and needs of the cancer early detection period might affect the adaption to, and coping with, a cancer diagnosis. Methods that men use to cope with the threat of a cancer diagnosis were identified in this study, such as planning and preparation, using humour and preparing themselves with information and knowledge. These findings could have significant implications for men's wellbeing during the cancer early detection period, with potential to contribute to support interventions. The highest ranked needs raise important points for consideration. Furthermore, it is evident that there is a wider research issue to consider the views of men during this period to address needs earlier on in the cancer continuum rather than waiting until they are in the treatment or survivorship stage. This chapter has illustrated the importance of four specific themes, including the importance and value of social support for men. Men value the opportunity to understand and learn from a peer who has been through the cancer early detection period. However, accessibility to peers with similar experiences was problematic. The next chapter will explore a unique and novel method to share experiences of the cancer early detection period digitally for the purposes of benefitting other men.

Implications and future research

The findings highlight the important role HCPs have in facilitating consultations during the cancer early detection period. The evidence suggests that there is as much a need for a compassionate, inclusive, empathic approach during the detection period, as there is at other stages of the cancer trajectory (Carter et al*,* 2011; Ervik, Nordoy, & Asplund*,* 2010; Galbraith, Hays, & Tanner, 2012; Milne, Spiers, & Moore, 2008; O'Brien et al.*,* 2010, 2011; Ream et al, 2009; Thomas, 2013; Walsh & Hegarty, 2010). The impact of effective communication and increased involvement in consultations is improved clinical encounters, which have the potential to lead to improved satisfaction and better outcomes (Bourke et al., 2012; Corboy, McDonald, & McLaren, 2011).

It is widely acknowledged that recruiting men into health research can be challenging. The venue or setting used to conduct health intervention research has been identified as a crucial factor in their engagement with health (White & Witty, 2009). Health researchers may use venues in NHS settings due to the ease of accessibility, convenience and low cost. However, the disadvantages associated with using an NHS venue have been cited as prohibitive for some participants due to the association with medical testing or procedures. One of the ways to address these issues, to attract men and make accessibility easier, is to hold the research in a non-health setting within a community venue. Going out to reach men where they naturally socialise, such as at sporting venues, has been shown to be important and effective (White & Witty, 2009). However, it is recognised that there are both advantages and disadvantages of using a football club as a venue for the purposes of this, and future, research.

There is an increase in the use of professional football clubs as settings to attract men to activities related to health in the United Kingdom (Brady et al., 2010; Pringle, McKenna, & Zwolinsky, 2013. The evidence for using them to engage men with health research is gathering momentum (Bingham et al., 2014; Curran et al., 2014; Parnell et al., 2013; Pringle, McKenna, & Zwolinsky, 2013). In 2013, the NHS Confederation published a report highlighting that *"sports clubs often have attractive, iconic premises which fans feel comfortable accessing, and which can provide an idea/location"* (NHS Confederation, 2013, p2). The report recognised that the appeal of professional football clubs to many men represents a unique opportunity for reaching men and engaging in a “male-friendly” way (NHS Confederation, 2013, p5). There are numerous benefits of using football clubs as a vehicle to attract and engage men with health interventions and research. The “brand” of the club, and what it represents to men in the community, is a major pull factor (Bingham et al., 2014). To be surrounded by the pitch and club memorabilia enables men to gain an ‘insider’ view which may provide a sense of physical and symbolic closeness to the club (Hunt et al., 2014a; Hunt et al., 2014b). To be with other likeminded men - who also support the team - adds value to the experience. However, it is important to consider the numerous alternatives to using sports club venues for conducting research with men as they will not provide the same attractiveness to all men. Other studies have found success when utilising environments where men naturally congregate such as: workplaces; barbershops; and bars (Hood et al., 2018; Macdonald et al., 2004; Ohnishi et al., 2012) as venues to engage men in health research. Using a range of venues to engage men in health research is advantageous to engage those men whom a football club venue may not provide the same ‘pull’ as football is not valued or seen as important. In some geographical areas the use of a football venue may even act as a deterrent for some men, and prevent them from engaging, as they would not want to be associated with a certain club (Benkwitz & Molnar, 2012). In particular regions there are fan-based issues relating to social identity as a member and association with rival clubs which can create a barrier to engagement (Benkwitz & Molnar, 2012). For example, in the West Midlands, some Birmingham City fans may be reluctant to attend a focus group at Aston Villa football ground, as there is strong rivalry between the clashing of subcultural fan bases (Benkwitz, 2013). Researchers conducting research studies need to carefully consider these factors and weigh up the pros and cons of using a football club, as a venue, over others.

Limitations

The cohort consisted of individuals who were part of a prostate cancer support group and thus not necessarily representative of men undergoing testing within the general public. It is possible that men self-selecting to be part of this study introduced bias into the study, as they had an active interest in self-management or cancer research. In addition, it should be acknowledged that the study participant sample contained individuals who were comfortable with taking part in a group workshop. It is recognised that the use of a different method to prioritise the themes may have resulted in a different type of relationship between the researcher and participants, impacting on the findings. Therefore, potential bias and interpretation of the findings must be carefully considered given that this study is based on a small specific sample, caution should be taken in generalising the findings across to other groups of men. Another limitation was the issue of time lapse since experiencing the cancer early detection period, which varied across the group. Therefore, recall may have been an issue for some study participants. However, the average time since diagnosis of the participants was 24 months and so a good proportion had recent experience, with the maximum time since diagnosis being 50 months. As this study did not include men without a partner, further research is suggested to identify the impact of the cancer early detection period, with the heightened risk of distress, on men without a supportive individual, partner or peer group support.

Conclusion

This study has enabled the identified support needs, and requirements, of men during the cancer early detection period to be prioritised in order to improve psychosocial issues. Men want to feel in control during the period of uncertainty and identified four themes of need, with the highest priority of needs relating to: planning and preparation; having effective communications with HCPs; social support, and; accruing information and knowledge. These findings could have significant implications for men’s wellbeing during the cancer early detection period, with potential to contribute to support interventions intended to improve: planning; effective communication skills; social support, and; accruing information and knowledge.

Chapter 5 – Development of digital stories, and evaluation of the storytelling process, to co-design narratives with men about the cancer early detection period

Introduction

In the previous chapter, one of the highest prioritised needs was the ability to access peer support. Value was placed on gaining insight, knowledge and connection with other men's experiences. However, many barriers - including the brevity of the cancer early detection period - presented significant challenges to accessing other men with experiential knowledge. In accordance with the wider aim of the thesis, the previous study identified the need to find a way to support and enable men to access other men's experiences to gain peer support during the brief period. This focused the design for the next study, outlined in this chapter.

Wider research has found that hearing others' experiences of illness through the use of peer narratives or stories can: reduce fears and boost confidence (Lowe et al., 2009); increase the relevance of information (Broemer, 2004; Sillence et al., 2007); help the comprehension of future events (Lowe et al., 2009; Rothman & Kiviniemi, 1999), and; alter the appraisal of the illness (Zufferey & Schulz, 2009). Therefore, reflecting the need to enable men to access other men's experiences during the period, this study was designed to facilitate a process to capture what men wanted to communicate, to other men, about the cancer early detection period. During times of illness and disruption, such as the cancer early detection period, it has been suggested that hearing peers' stories could help to make sense and give meaning to the experience (Abma, 2005; Bosticco & Thompson, 2005) by providing reaffirmation (Atkinson, 2002). The information and advice offered through narratives is powerful, as it is grounded in the lived experience of what has benefited others. It is valued for its pragmatism (Sandaunet, 2008; van Uden-Kraan et al., 2008), relevance and ease of understanding (Steffen, 1997). Narratives or stories are a powerful way to communicate with and engage individuals. They provide a mechanism to transfer learning (Hinyard & Kreuter, 2007; Houston et al., 2011; Larkey & Hecht, 2010) and understand other people's experiences, including the challenges they have faced.

Being able to access resources and peer support at a convenient time, in private, without compromising perceived masculine ideals (such as emotional self-sufficiency), breaks down potential barriers to health seeking for many men (Courtenay, 2000; Lohan, 2007; Pollard, 2007; Robertson, 2010). Therefore, given the findings from the previous study, and the aim of this study, digital story telling provided a tool to collect data, with a process to develop narratives for unheard voices. By evaluating the novel approach, with an onus on participants' experiences, the chapter will provide understanding of the potential of the process to bring benefit for other men. As detailed earlier in Chapter 1, the UK Medical Research Council Framework for the Development and Evaluation of Complex Interventions (Craig et al., 2008) provides the structure for each of the chapters. This study seeks to explain the process of applying Phase 2, Stage 3 (visual rendering of the narrative and concepts) of the Framework specifically to creating digital stories as a peer support resource that will enable men during the cancer early detection period to transfer knowledge between peers, as a standalone resource or embedded within the wider online intervention.

Narrative persuasion is a well-established psychological theory (Green & Brock, 2000): the opportunity to listen to others' cancer-related experiences creates a space in which people can reflect on their own situation, consider changes, and provide hope for a healthy future (Banks-Wallace et al., 2007). Cancer narratives produce stronger cognitive and affective responses than cancer information alone, which influences message processing and behaviour, and reduces counter-arguing (McQueen et al., 2011).

Using narratives to engage with men and provide peer support has the potential to positively influence men's well-being, rebuild hope and aid decision-making (Meyer, Coroiu, & Korner, 2015). The importance of social relationships and being connected to others is illustrated by the positive impact it has on mortality and recovery (Dennis, 2003). Peer support has been found to help men express their experiences of illness, and share knowledge and thoughts, making them feel less isolated (King et al., 2015). The opportunity to share with other men has been found to be empowering and to provide meaning to men's experience of cancer (Galbraith, Hays, & Tanner, 2012; King et al., 2015), even when the information provided is not positive (Krumwiede & Krumwiede, 2012). Therefore, it could be argued that using narratives to engage with men and provide peer support, during the cancer early detection period, has the potential to add benefit even though it is a short period of time.

Peer support is a preferred option for men, over professional-only support, as it is viewed as unobvious help-seeking (Robertson et al., 2015). However, for peer support to be effective for men, it needs to ensure it embraces gendered identities (Seebohm, Munn-Giddings, & Brewer, 2010). Engaging men face-to-face with health issues and information presents a challenge that may be better met by online sources (Lohan et al., 2015). Sources of information and support that are web-based allow men with cancer to access, and freely share, sensitive topics that they perceive to be difficult to do in a face-to-face context (Broom, 2005). With the anonymity to distance themselves, and a perceived ability to be objective, web-based sources provide a freedom for men that is advantageous (Rising et al., 2017). Web-based narratives offer promising advantages to providing peer support, during the cancer early detection period, with the potential to provide men with a forum to benefit from during the time-limited period.

Arts-based research

A growing body of research has demonstrated that creative engagement, through arts-based approaches, aids the mitigation of distress (anxiety and depression) and contributes towards optimal health and wellbeing (Caldwell, 2005; Camic, 2008; Cox et al., 2010; Sonke et al., 2009; Stuckey & Nobel, 2010). Creative processes are recognised for their ability to improve mood, by enhancing emotional wellbeing, and increasing cognitive function (Bolwerk et al., 2014; Castora-Binkley et al., 2010; Stuckey & Nobel, 2010). An increasing interest in the potential impact of the arts within health and wellbeing has been facilitated by the rise in evidence of its ability to reach a wide variety of people (Davies et al., 2014; Sonke & Baxley, 2015). Arts-based research has flourished recently (Boydell, Solimine & Jackson, 2015; Lenette, 2017), with a growing evidence base of the positive impact for individuals with cancer (Haltiwanger, Rojo, & Funk, 2011; Puetz, Morley, & Herring, 2013; Stuckey & Nobel, 2010; Visser & Op ‘t Hoog, 2008; Waddington et al., 2007).

The use of arts-based research within qualitative research has flourished recently (Boydell, Solimine & Jackson, 2015; Lenette, 2017) with a growing evidence base of the positive impact for individuals with cancer (Haltiwanger, Rojo, & Funk, 2011; Puetz, Morley, & Herring, 2013; Stuckey & Nobel, 2010; Visser & Op ‘t Hoog, 2008; Waddington et al., 2007). Interventions using the arts could address some of the challenges that cancer brings, including life disruptions and reconstructions of identities (Lee, 2008; Lee et al., 2006a, 2006b), such as those related to gender.

Using arts or creative methods brings a fresh interactive approach and different perspective (Dunn & Mellor, 2017; van der Vaart, van Hoven, & Huigen, 2018). Within health care it is imperative to find different methods to understand complex issues, such as cancer, to gain a deeper understanding of the subjective nature of experiences (especially for harder to reach communities). In western culture, value is placed on rational-cognitive ways of knowing (Lawrence, 2008), whereas emotional - or embodied ways - may be dismissed, as they produce less objective data that can be ‘tested’ (Foster, 2012). Arts-based research provides the opportunity to cut across disciplinary boundaries and practices (Foster et al., 2007), offering new understanding of complex issues. The value of the emotional connection conveyed through arts-based approaches facilitates the opportunity to enhance engagement for audiences (e.g. Levin et al., 2007) and individual research participants, through the provision of a forum for reflection and expression (Saunders, Hammond, & Thomas, 2018). It provides the potential to generate data much wider than other methods (e.g. Dyches, Smith, & Syal, 2004; Oliffe & Thorne, 2007), as a deeper understanding of experiences and issues is enabled through the process (Saunders, Hammond, & Thomas, 2018). The unique approach adds value through the opportunity it provides to communicate and transfer knowledge and findings far beyond academia, to the general public (Boydell et al., 2012; Colantonio et al., 2008; Keen & Todres, 2007). Lastly, arts-based methods produce research with, rather than on, participants (Bostock & Freeman, 2003; Cahill, 2007; Salmon, 2007).

This study has utilised participatory design techniques (Bason, 2010; Bate & Robert, 2007; Parker & Heapy, 2006; Voorberg, Bekkers, & Tummers, 2015) which are based on a parity of esteem (between participants and the researcher), with mutual respect for reflexivity and fluidity. The user-led co-design approach adds to the case for change in dispelling the assumption that men do not participate in creative activities (Geue et al., 2010; Hammond et al., 2018), and contributes to the field exploring men’s experiences of engaging with arts-based approaches within the field of cancer (Saunders, Hammond, & Thomas, 2018).

User led co-design approaches enable citizens to ‘play an active role in producing public goods and services of consequence to them’ (Ostrom, 1996: 1073). Credibility of each voice is recognised, bringing the legitimacy of knowledge every person brings and contributes, readjusting the balance of power (Boivin et al., 2014). The approach, facilitated through the process of using arts-based approaches, enables the redress of aspects related to power, including ‘language’, ‘self-expression’ and ‘presence’ (Bourdieu, 1991; Fairclough, 2001; French, Raven, & Cartwright, 1959). Professional and research specific language is exclusive; through the use of arts-based methods, the voice of the creator can be communicated and speak to a wider lay audience.

Visual media

In comparison to verbal or text-based communication, studies suggest that visual media is more memorable (Gardner & Houston, 1986; Paivio, Walsh, & Bons, 1994; Prabu, 1998), has a better impact (on intention towards preventative health behaviours) in the long run (Cameron, 2003), and is not as dependent on literacy or language levels (DeWalt et al., 2004, Williams et al., 2012). The use of images to illicit changes in behaviour and mechanise change within the health field offers power and promise, as they are known to influence behaviour through emotion and cognition (Bradley & Lang, 1999; Ito, Cacioppo, & Lang, 1998; Williams et al., 2012). The use and understanding of visual media to communicate messages with others – termed 'visual literacy' (Ausburn & Ausburn, 1978; Avgerinou & Ericson, 1997) – extends the reach to wider groups of the population. It provides opportunities to reach groups for whom face-to-face health-related information is more challenging, as traditionally-shared experiences and support have been stifled by men's reluctance to engage in the process. Visual media provides men with the option to disengage at any point, without having to give an explanation or feel any embarrassment in front of others. Other studies have shown that by giving men an element of control over the extent of their involvement, with support interventions (Oliffe et al., 2010; Sandstrom, 1996), can increase their acceptability. In other supportive forums (such as in online or in-person support groups), men place value on having the option to be present, but also listen without the expectation to contribute. Arts-based methods using visual media, such as digital stories, offer and extend this opportunity as a possible alternative mechanism to develop self-efficacy and confidence, communicate peer empathy, and share experiences (Cockle-Hearne, Cooke, & Faithfull et al., 2016). Evidence indicates that visual materials that include images of real men, and normalise experiences, make them more acceptable and more likely to engage others (Anderson et al., 2016). Therefore, it is suggested that using visual media offers opportunities to reach men in groups for whom face-to-face health related information may be more challenging.

Digital storytelling

Within the field of healthcare, digital stories have been used as a method to aid the understanding of the experiences of patients and healthcare professionals (Akard et al., 2016; Clarke, Hanson, & Ross, 2003; Cumming et al., 2010; Larkey et al., 2009; Williams-Brown, Baldwin, & Bakos, 2002). Digital stories are short, 3-5 minutes in length, and use first-person video narrative developed through a combination of photos, video images, music and voice (Storycenter, 2016). The story is created by using multimedia tools and illustrated through a medley of video clips, narration and music (Christiansen, 2011; Gazarian, 2010).

Studies using digital stories with people affected by cancer have found that they are effective in improving education on cancer screening practices (Larkey et al., 2009) are effective teaching tools (Clarke, Hanson, & Ross, 2003; Cumming et al., 2010; Williams-Brown, Baldwin, & Bakos, 2002), mitigate suffering (Laing et al., 2017a) and provide potential improvements for quality of life (through the open expression of emotions) (Akard et al., 2016). Outcomes of digital stories include: feelings of achievement for the story teller (Anderson, 2009; Davis, 2004; Davis & Weinshenker, 2012) and a mechanism in which to communicate to a wide audience about an experience, enabling it to be seen and easily understood (Wilson, Hutson, & Wyatt, 2015). Theories of post traumatic growth highlight the key role reflection plays in evoking positive responses, and adjustment, from traumatic experiences (such as cancer) (Tedeschi & Calhoun, 2004). Digital stories place the author of the story at the heart of it and provide the individual with an opportunity to reflect and apply their own interpretation and meaning to the experience. They have the ability to engage and empower vulnerable groups to share their experiences to advance social inclusion (Rice et al., 2015), highlight important issues and influence for social change (Boydell et al., 2012). However, the process of inviting participants to think back to a time that may have been distressing, and encouraging them to discuss and engage with the experience, may evoke painful memories. Researchers need to be prepared for the possibility that participants may revisit traumatic events, as part of their storytelling, which may cause them to experience distress (Stacey & Hardy, 2011; Spector, Smojkis, & Chilton, 2011). Therefore, preparation is key and researchers using digital story telling need to have planned carefully for this potential scenario including providing a safe space for participants and having the skills to deal with participants if they become distressed. The inability to provide these resources, and develop these skills, may prohibit the use of digital story telling as a method for data collection for some researchers.

Numerous studies have found that stress and self-blame, associated with stigma, are common experiences of people affected by cancer (Conlon et al., 2010; Else-Quest et al., 2009; Gulyn & Youssef, 2010; Holland, Kelly, & Weinberger, 2010; Vodermaier, Esplen, & Maheu, 2010). Cancer is still a taboo for many men and viewed by some as a death sentence, telling and hearing stories from people belonging to a stigmatised group has a transformative effect (Naslund et al., 2015; Newhouse, Atherton, & Ziebland, 2017; Ziebland & Wyke, 2012). The counter-narrative digital stories offer is important, as they provide an alternative interpretation of identity and experiences associated with inequity or stigma (de Jager et al., 2017). Therefore, when conducting narrative research, particularly with sensitive or taboo subjects, it is imperative to approach the research with great care and sensitivity to prevent further marginalisation or objectification of individuals

(Hendry, 2007). Within DST methodology there are ethical tensions acknowledged between the need for confidentiality (Cunsolo Willox, Harper, & Edge, 2013; Evans & Jones, 2008; Lenette & Boddy, 2013; Willis et al., 2014) and individual ownership and 'voice' (Cunsolo Willox, Harper, & Edge, 2013; Lenette & Boddy, 2013; Spector, Smojkis, & Chilton, 2011) whilst preventing further stigmatisation of certain groups. Willis et al.'s (2014) study highlighted this tension as participants had a desire to share their 'voice' about living with HIV but feared the potential stigmatisation from sharing their stories publically.

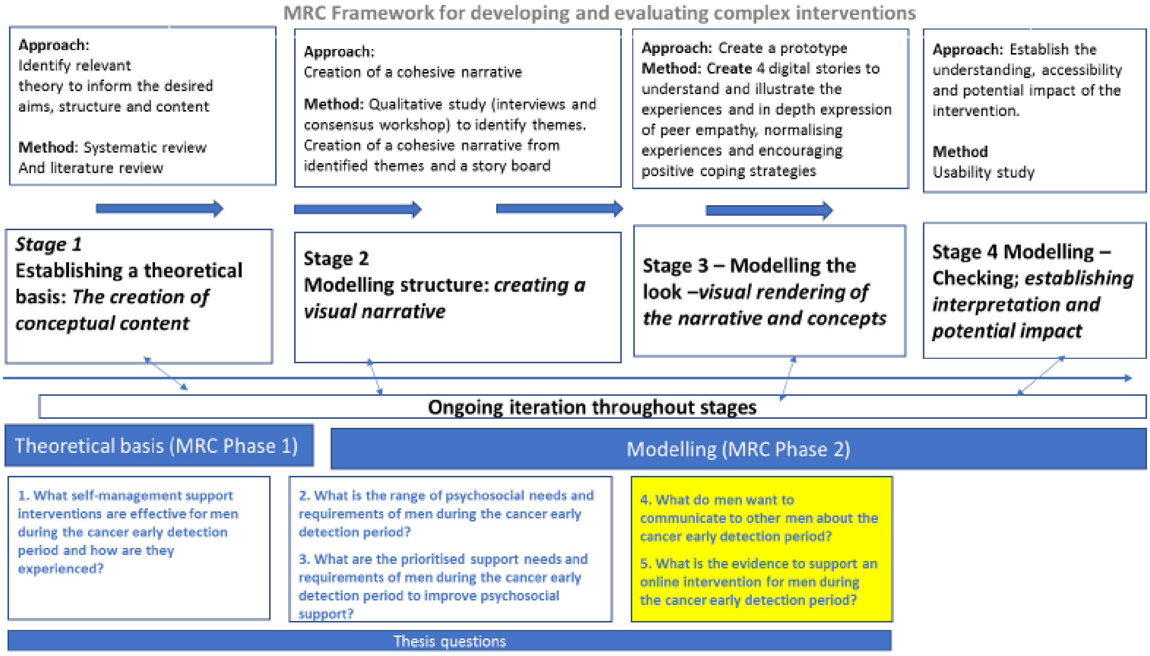
Studies conducted with people affected by cancer suggest that in addition to the therapeutic value, digital stories highlight the psychosocial impact (Laing et al., 2017a). It could be argued that by highlighting the psychosocial impact of cancer, the audience is in a better place to understand the experience and emotions of the individual telling the story. Facilitated through the multi-sensorial nature, digital stories provide insight into the experience of the individual storyteller at a far deeper level than is possible through text alone. Therefore, the connection of experience is reflected at a greater level through the voice of the storyteller, the pictures they choose to include, and the visual footage. However, given the fluid and iterative nature of the method, the researcher needs to be prepared for the possibility that, even when a topic or parameters are set with participants, there is the potential for story tellers to go 'off topic' and the researcher needs to build flexibility into the process to allow for this.

Although digital story telling offers advantages to both the individual storyteller and the audience (Akard et al., 2016; Clarke, Hanson, & Ross, 2003; Cumming et al., 2010; Larkey et al., 2009; Williams-Brown, Baldwin, & Bakos, 2002) there are several other methodological factors, and ethical issues, that need to be considered. These factors are particularly important when working with sensitive topics and using digital story telling with seldom heard groups. There is acknowledgement within the literature that the DST approach takes a Westernised narrative form to creating and telling stories that does not corroborate with non-western story forms (Cunsolo-Willox, Harper, & Edge, 2013). For example, the DST structure suggests a succinct 3-5 minute story - with a start, middle and end - which does not necessarily match non-western traditions of storytelling which encourage ongoing open ended stories without conclusion (Cunsolo-Willox, Harper, & Edge, 2013). The limitations of time, and being succinct, can present a challenge leading to 'partial stories' being told and difficulties in deciding what the message should be (Boydell et al., 2017). Having the ability to edit and decide on which information to leave in, and which to take out, can present an additional challenge for some marginalised groups (Boydell et al., 2017). Therefore, it is recognised that the expectation, participation and skill level of participants may impose limitations on the extent of the use of digital story telling. Participants need to have, at least, a basic level of IT understanding and this requirement may prohibit and further restrict their engagement. In comparison to other research methods (such as conducting a survey), facilitating the DST process is highly time-consuming and resource intensive (training and costs associated with obtaining, and using, audio-visual and IT equipment), with a large degree of personal investment needed by the researcher. The process involves the researcher working very closely with participants, and it is imperative that they have excellent facilitation skills and experience of working with participants on sensitive topics.

However, arts-based methodologies that incorporate gendered experiences of cancer offer a promising approach to the design of interventions intended to improve the wellbeing of individuals with cancer (Saunders, Hammond, & Thomas, 2018). Research has identified the usefulness of stories in enabling health behaviour change (Hecht & Miller-Day, 2009; Komro et al., 2004) and potential outcomes for health promotion (Bertera, 2014; Houston et al., 2011; McQueen et al., 2011; Perez et al., 2014). Digital story telling as a relatively new data collection technique within health research offers researchers multiple opportunities to simultaneously create, and represent, knowledge of participants’ experiences (Lal, Donnelly, & Shin, 2015). It has been used as a research method both independently, and as a tool, which is complementary to other methods (Gray et al., 2010; Gubrium et al., 2016. The uniqueness it provides - over and above other traditional methods (such as questionnaires) - is the opportunity for participants to be actively involved in the process of eliciting the data, and analysing the content, deciding what is included to represent ‘their’ story. The main aim of this study was to use digital stories as a method to collect the experiences of men during the cancer early detection period, and create a peer support resource that will enable the experiences and knowledge of men with lived experience to be transferred for the benefit of other men going through the period (as standalone online stories, or embedded online stories within the wider online intervention). In order to allow the audience to decide if the findings are transferable to their situation or not a “thick description” of the research is provided (Holloway, 2008; Korstjens & Moser, 2017; Shenton, 2004). The verbatim narratives, provided through the digital stories of the participants' accounts, allow for other men (who watch the stories) to judge whether the context is sufficiently like their own situation (Holloway, 2008; Korstjens & Moser, 2017; Shenton, 2004) and gain benefit from understanding how other men have coped.

As detailed earlier in Chapter 1, the UK Medical Research Council Framework for the Development and Evaluation of Complex Interventions (Craig et al., 2008) provides the structure for each of the chapters. This study seeks to explain the process of applying Phase 2, Stage 3 (visual rendering of the narrative and concepts) of the Framework specifically to creating digital stories as a peer support resource that will enable men during the cancer early detection period to transfer knowledge between peers, as a standalone resource or embedded within the wider online intervention (see Figure 11). The study also captures the participants evaluation of the process of developing their own digital stories.

Figure 11 – MRC Framework – Phase 2 Stage 3



Aim

The aim of this study is to co-design narratives with men about the cancer early detection period to develop digital stories for unheard voices and evaluate the digital storytelling process. The study aims to answer this research question:

What do men want to communicate to other men about the cancer early detection period?

Method

In accordance with the aim of the study, and critical realist approach to the thesis, it was important to select a study design that would allow for the objective reality, through the subjective lens of participants, to be captured in the knowledge generation and interpretation. As qualitative research allows for a greater investigation of the impact of context (Braun & Clarke, 2013), and the exploratory nature of the study, a qualitative research design with a Participatory Action Research (PAR) approach was adopted. PAR is distinctive and unique, in comparison to conventional research (Baum, MacDougall, & Smith, 2006). It seeks to understand the world through self-reflective inquiry that enables action, provides equity in the relationships between researcher and participants, and facilitates contextualisation of the research by actively engaging partners.

The specific method chosen was digital storytelling (DST). Derived from Lambert and Atchley in the 1980s (described above), digital storytelling gives recognition to storytelling as a powerful natural vehicle for representing individual narratives of voices that may be difficult to hear or represent in more typical ways (such as those from hard to reach, marginalised communities). The process of digital storytelling offers the opportunity to gain inclusive insight, through reflection, as a way of creating meaning from diverse perspectives. The DST process is person-centred, with participants retelling their experiences and retaining control over the story that is told. The storyteller chooses the images, film, script, music and photographs, which are combined with their recorded voice. The study was designed to develop the content of the digital stories, and gain insight into the process, by using a two-staged approach which included:

Stage 1 – data was captured, and analysed, via the audio transcripts of the individual digital stories

Stage 2 - evaluation via a questionnaire (Appendix 16) at the end of the digital storytelling process

Participants

During December 2017, the researcher reviewed the interviews from the qualitative study (Chapter 3) and identified participants who explained how they coped and self-managed during the cancer early detection period. Using the evidence of effective coping strategies identified and outlined in Chapters 1 and 2 as a rationale for what was considered ‘effective’, the researcher identified participants who had previously made reference to using the strategies (during the one-to-one interviews in Chapter 3). The strategies varied and included for example: seeking social support and accessing peer support (shown to support and alleviate anxiety) (Krumwiede & Krumwiede, 2012); accessing shared activities such as sports (Hunt et al., 2014a; Hunt et al., 2014b); seeking information and accruing knowledge (Wiljer et al., 2012, 2013); reappraisal of thoughts; relaxation and mindfulness (Karwoski, Donnelly, & Shin, 2006). Participants who referred to using these strategies were sent an an email, and information sheet, inviting them to be involved in the digital storytelling project. Recruitment occurred during January 2018. Once participants registered an interest they received an information sheet (Appendix 17) and consent form (Appendix 18 to sign and to send back in a self-addressed envelope. Participants needed to be in easy travelling distance of the Midlands and to able to travel to the workshop venue. Five participants registered an interest, and a mutually agreeable date was agreed. Upon recruitment, participants were asked to bring with them photos, pictures and objects that were meaningful to them and which illustrated the story of their experiences during the cancer early detection period.

Taking into account the purpose (Patton, 1990; Sobal, 2001), all five participants who registered an interest were selected because of their effective coping strategies and personal experiences of the cancer early detection period. The researcher identified participants effective coping strategies, using the evidence identified for strategies in Chapters 1 and 2 (such as: seeking social/peer support, sharing activities like sports; seeking information/ knowledge; reappraisal of thoughts; relaxation and mindfulness). Malterud and colleagues' (2016) concept of 'information power' was used to guide and evaluate the sample size for the study. In line with this concept, the greater amount of information held by the sample, specific to the study, the lower the number of participants required. With a narrow study aim, participants recruited were highly specific for the study, with a dense amount of pertinent information (ascertained through the previous qualitative interviews, outlined in Chapter 3). Participants had to be aged ≥18 years and to have been through testing for any cancer type. One of the participants contacted was not included in the workshop due to ill health.

Procedure

The researcher and participants re-read their own telephone interview from the previous qualitative study (as outlined in Chapter 3) and agreed on the aspects of the experiences to concentrate the story on. It was imperative to listen to participants actively to understand experiences from their perspective, exploring the meaning attached to the experience. Engagement with participants on an individual basis facilitates a willingness to share information about sensitive subjects which may not be possible through other approaches (Gill et al., 2008), allowing for both depth and breadth of data to be captured (Britten, 1995).

Stage 1 – In line with a staged approach to digital story production (Lambert, 2010), participants were invited individually to take part in a DST workshop to retell their story (Lambert, 2010), in the context of their lived experience of the cancer early detection period. It was imperative to create an environment that was relaxed and comfortable for participants in which to create and retell the story of their experiences. To ensure ease of access for the participants, a venue was chosen that was equidistant and central to where participants were travelling from within the Midlands, with plenty of transport options and ample parking. As the multimedia equipment was also a consideration, a venue on Birmingham University Research Park was chosen. A date and time was agreed with the participants who had registered an interest to ensure that retention was maximised. To break the ice on arrival, participants were invited to have lunch and an informal chat with the researcher and audio-visual expert. The participants were introduced to the equipment. This introduction, alongside having some refreshments, created a relaxed environment. The workshop then followed and focused specifically on the experiences of the participant.

The researcher worked with the participant on a one-to-one basis and digital stories were crafted within the structure of the workshop that featured talking and writing prompts, individual script work, script-editing, voice recording of scripts, image selection, and digital editing and assembling. Participants were given different time slots to ensure sufficient time was allocated to each individual. All of this was done with guidance from the researcher and AV expert. Story prompts were used to encourage participants to write about their experiences of the cancer early detection period. The prompts included some directive, topical questions to encourage participants to think back to their experience of the cancer early detection period. For example: *think back to the time between having screening (or a test) and then receiving the results of the test, what do you remember about that time?* Then broader questions were asked to gain understanding about their perceptions during the period: *Think about how you felt during the time leading up to getting your test results, can you describe some of those feelings?* In addition, they were prompted to think about how they coped, and what strategies they found useful, for example: *What different coping strategies did you use during the period?* They were asked to think about, with hindsight, what they would like other men to know and what information they would like to pass onto other men going through the period. Participants received feedback each step of the way—from the researcher and AV expert in one-on-one contexts. Their stories evolved as they worked with feedback. Recordings were made using a video recorder, which facilitated both the audio and visual components of the digital story. The recordings lasted between 39 and 60 mins. The researcher asked the participant about the objects, photos and pictures that they had brought with them to depict their story visually. Only one participant did not want to use photos and opted to be filmed at work to illustrate his story further. Edited stories ranged from 6 minutes to 15 minutes and were sent to participants via an emailed ‘unlisted’ YouTube file. The informed consent form included a check box where participants chose to allow or not allow sharing of their video for research purposes or examples to show other men. All participants in this study agreed to share their digital story. All full scripts were transcribed verbatim.

Stage 2 - Upon completion of the digital story process, participants were asked to complete a 3-page, written evaluation (Appendix 16), with open-ended questions, to share their experiences of specifically creating a digital story with their reflections on the whole process. To meet Coventry University guidelines for studies undertaken by students, an ethics application was submitted, and approval granted by the Health and Life Sciences (HLS) Ethical Committee ID: P66320.

Analysis

Inductive data-driven thematic analysis was chosen as the most appropriate method for the analysis (Braun & Clarke, 2006). This included: 1) transcriptions of the digital stories, and; 2) an evaluation questionnaire at the end of the digital storytelling process. Thematic analysis is a useful method to identify, describe, analyse and report patterns and themes within the data. The analysis followed the six-phase process by critical reflection (see Appendix 6) (Braun & Clarke, 2006). The inductive data-driven approach was beneficial (as outlined in Phase 2 ‘generating initial codes’ and Phase 3 ‘searching for themes’ of the process) as it allowed for the identification of unexpected themes within the data (Braun & Clarke, 2006).

The audio narratives from the four digital story films produced were transcribed. The transcripts were individually read twice by the researcher and examined in depth and notes were made. Initial coding was applied with the purpose of being open to many interpretations. The codes applied described participant’s experience or thoughts and where possible links were made between identified needs and coping mechanisms. Development included the constant review of the incorporated areas of interest from the interview schedule, which led to new, emerging codes. The codes were reviewed after each interview and revised to include the new emerging codes. Once coding was complete, focus was given to identifying the themes. Braun and Clarke (2006) definition of a theme is something that captures a meaningful aspect of the data in relation to the research question. The identification of themes was an iterative process that enabled the development and emergent of themes, the highest level of coding. Constant comparison and review of the themes enabled progression to focus on establishing the sub-categories of themes which became evident, and lower levels of coding were highlighted (Braun & Clark, 2006). The codes and themes were organised using NVivo 11 software.

The analysis of the evaluation data, collected via the questionnaires, were coded using the same iterative process (as described above), to generate themes associated with participants subjective interpretations of the digital storytelling process. The researcher carried out the initial analysis and the emerging themes were reviewed independently by another researcher in the supervision team. Discrepancies were resolved by discussion with the other researcher involved. Codes were grouped into categories and emerging themes were then identified, following the principles of thematic analysis (Braun & Clarke, 2006).

Findings

The cohort (n=4) of consented participants (Table 16), included a range of demographics and lived experiences. Of the cohort, two participants were White British, one was Black British, and one was White Irish. Ages ranged from 53 to 71 years (median 59 years).

Table 16 – Study participants

		Study Participants
Age at interview	Mean	59 years
	Range	53 - 71 years
Relationship Status	Single/divorced/separated	1
	Married	3
Sexual orientation	Heterosexual	3
	Gay	1
Cancer tumour site	Prostate	2
	Bladder	1
	Testicular	1
Time since testing	Mean	16 months
	Range	5 - 29 months
Cancer diagnosis	Yes	3
	No	1

Stage 1 - results

A peer resource - content of Digital Stories

Throughout the digital stories, participants talked about their experiences of the cancer early detection period, providing parallels between life before, during and after the period. Participants selected meaningful objects, photographs and images that illustrated the experiences and coping strategies used, to support the visual aspect of the story. These included photographs and images of family, friends, holidays and a range of objects, or props, which were used to represent hobbies and work. The researcher used a set of semi-structured questions to help guide individuals to think about key aspects of the period and to support the development of the story's structure, with a beginning, middle and end. Although guidance was provided, participants selected what they wanted to talk about within the story and what messages they wanted to communicate to inform other men and support coping within the period.

Digital story 1

Participant 1 - https://www.youtube.com/watch?v=4qCF0k_RKrU&feature=youtu.be

P1 chose to be filmed at work, typing with gusto on his computer and answering the phone, illustrating 'busy-ness', swapping tasks at speed and displaying concentrated effort in his work through his body language. He dressed in a full suit and appeared neatly presented. He chose to be filmed to illustrate his need to continue with 'normality' during the period and described using emotion-focused coping strategies, mainly distraction and suppression, facilitated by keeping busy at work. He talked about the need to keep in control primarily through problem-focused coping, particularly planning which was very important to him. He acknowledged the anxiety he experienced during the period and talked about his reluctance to engage with social support or wider use of emotion-focused coping. Part of this he attributed to being single and independent. With hindsight, he recognised how his behaviour, reluctance to seek social support and address the potential threat, impacted on outcomes and brought wider consequences:

> *"when I bottle it up, […] when I just keep busy and do stuff, sometimes I will leak stuff then, so I don't contain it well. So I might use humour inappropriately, in terms I might make joke about something to do with this situation. I remember, in relation to this, I did do that. In the wrong context so I wasn't managing it as well as I could."*

He recognised the time limit of effectiveness for some of the coping strategies he was using and was keen for other men to learn from his experience recognising the negative consequences of suppressing emotions. He identified how reframing perceptions of accessing social support by ‘doing it for others’ (rather than oneself) offers opportunity to break down help-seeking barriers:

> *“… it’s ok to talk to other people about it. There’s something in my coping strategy which is around not wanting people, […] not allowing other people to help actually. I kind of have that thing, I need to sort it. I need to do it. I’m very independent in that way.”*

The appraisal of ‘manageability’ and ‘controllability’ were aided by seeking information about the potential next stages and he recognised how attending the gym was a positive coping strategy during other periods of stress.

Digital story 2

Participant 2**-** https://www.youtube.com/watch?v=1bhWqdpM5Xg&feature=youtu.be

P2 chose photographs of his family to illustrate the support they gave him during the period and images of an artist’s palette (and easel) as art and other hobbies enabled him to relax and cope better during the period. P2 began his story by describing his initial appraisal as one of shock and *“a bolt out of the blue”.* He attributed some of this shock to the fact that his doctor had reassured him that it was something minor. Within a short space of time, he found himself going from a PSA test, to a biopsy, to a scan and how the waiting period impacted on him psychologically and led to psychosomatic tension and anxiety:

> *“waiting for that […] I don’t think I get stressed very easily because of the sort of job I’m in […] but I was obviously having an awful lot of tension and that was leading to getting some severe or some back pains. You’re almost convinced that something is happening […] I wasn’t particularly bad until I actually went to Dublin on my holidays for four or five days but I had a bit of time to think and then I had a couple of doubts and I woke up in the night just […] convinced you know that I was, that I definitely had got something in my bones, […] that obviously probably would be mean a shorter life expectancy and things like that. You start to think that, well, you know, what will I do, these sort of things go through your mind.”*

After the initial shock, he moved quickly to acceptance, and acknowledged how his supportive family and good social support network impacted on his ability to manage during the transition period. However, he described how he noticed that being male had an impact on his emotional inhibition and acted as a barrier to enabling him to open-up emotionally with other people. There was recognition that by talking to people he could have improved his coping experience:

> *“I guess I’m a bit like a lot of blokes really, I tend to keep a lot of things in and not take things home with me […] I was bottling things up and thinking I’d deal with an awful lot of it generally on my own as it were. […] I thought I was dealing with things quite well but at the back of my mind and at late at night […] an awful lot of tension […] which was quite bad and that was difficult [...] so I guess some of the, not letting out some of this, the feelings, and talking to people like perhaps I should have been a little bit more, […] a consequence of giving me more tension and knotting up a little bit.”*

He spoke of a number of coping strategies he used during the time, including talking to healthcare professionals and visiting credible information sources such as the Prostate Cancer UK website. He highlighted the effectiveness of peer support and talking to those who had been through the experience themselves. One of the most effective strategies for him was distraction through work, which facilitated the opportunity for him to release his emotions in a number of ways, giving him time away from others. He describes how work provided an opportunity for coping through physical activity, and cognitive space for emotional release:

> *“I’ve always had a decent walk during the lunchtime to stop me from getting too sort of beat up during the day and that helped as well and also I did quite a lot of walking after work during the evening as well so that, in terms of coping mechanism, was some form of exercise”*

Digital story 3

Participant 3 - https://www.youtube.com/watch?v=pZm0ohr4pSA&feature=youtu.be

P3 found meaning through his hobby of coaching and playing basketball during the time of disruption, and to illustrate this visually in the digital story he chose to show a basketball whistle and programme to reinforce the message. He was keen to communicate that he received no judgement and good support from his social network (and his family), and he recognised how without such support there is the potential for other consequences: *“It can make you feel very isolated, probably take you, […] down* *into depression"*. He talked openly about the wider pressures he felt about being a man, issues of masculinity, concern for the family and the impact if he wasn't around anymore:

> *"…from a male perspective, it's difficult. I'm the keeper of my castle, I pay the bills, I provide for my family, all that kind of thing, all that stuff is put at risk. And when that put at risk you're going, how's everyone gonna cope without me?"*

He identified his appraisal of the period as one of heightened risk, with several other factors that may have contributed, such as being a husband and a father with dependent children, and perceived cultural expectations and responsibilities. It might be suggested that the severity of threat was contributed to by the impact that the potential diagnosis could have on the quality of life of his wife and children. Although he initially described not knowing what to do to help himself, the coping mechanisms he used were effective in helping him to manage by reframing the experience and re-evaluating his life. As he began to come to terms with the experience, the effectiveness of using his social support network and embracing normality through his hobbies (basketball) enabled him to gain a fresh perspective. He ended his digital story by talking about how his personal experiences of coping led him to gain a positive outcome offering peer support and a desire to help others going through the same experience. In particular, he focused on how he wanted to support men from the same ethnic community:

> *"being able to talk to someone about that particular issue. In terms of preparation, […] be able to talk to someone who's experienced it. […] We don't own our own health particularly well so what we need to do is offer a shoulder to say ok, let's talk about this. I've been there, and particularly when you tell everybody particularly in the African Caribbean Community, you need to get your PSA done, it's an indicator […] to tap up a lad in their local area that feels they could offer support to another individual just to have a chat, have a beer, talk it through. […] I would want to be supported that way."*

Digital story 4

Participant 4 – https://www.youtube.com/watch?v=q-BmSBqN_W8&feature=youtu.be

P4 found the comfort and support of his family helped him to cope during the period and choose photographs of them to illustrate this visually in the digital story, to reinforce this to the audience. He talked about his experience of being initially in denial, and attributes this to beliefs formed through previous close family members' cancer experiences. He talked about how being in the state of denial helped him initially, as he experienced little anxiety or worry during the period:

> *"I just wiped that out of my mind 'cause I didn't think I would have, cause I thought if you've got cancer, you're going to feel ill and I didn't really feel ill […] I can't see anything. Because it was hidden, it was hidden inside whereas my only other experience was it being a visible cancer so I wasn't all that bothered in that respect."*

He acknowledged how the appraisal of denial contributed to his diagnostic experience, as when he did receive the results he was *"very surprised"*. However, he reported that his positive optimistic outlook resulted in him moving very quickly to a state of acceptance:

> *"I wasn't worried about it. I can understand some people would be. I'm a half, I'm a glass half full sort of person so I tend not to worry."*

His appraisal of the period as 'manageable and treatable' was facilitated by using several emotion-focused coping mechanisms during the transition period. He talked about the effectiveness of social comparison as a strategy. Comparing his situation to his two daughters' cancer experiences put his own into perspective, and made it seem insignificant:

> *"it was very minor after what my two daughters had […] I almost felt like a fraud. That's how I felt then because what I'd got was nothing to what they'd dealt with. I think that in a way, yeah, thinking about it, I've never put it into those terms, […], what they'd gone through at their age, forty years younger than me, what they'd had to go through and put up with, I was relatively minor if any sort of cancer can be called minor, but that's how I felt. […] because they'd had such a rough time with all sorts of treatment, chemo, radio and herceptin, mixes all their bodies around. Compared to what I had, […] I feel like a fraud. In a way, I'm not in the same league as them, compared to what they've had, so, no what I've got, knowing what they had and how they got through, I thought well, I'm a bit older than that, I'm sure I'll get over it. The rest of your health needs to be right, good for my age I suppose, I've got to be right."*

He recognised how the fear and self-blame that other individuals may experience can act as a barrier during the period, and was keen to encourage other men to be proactive and not put off seeking help. By acting quickly, he was keen to urge other men to be positive and seek help to keep control: *"don't be negative about it because it isn't something you've done, something has happened to you".*

Themes across the digital stories

The following two themes emerged from the content of the men's digital stories: 1) Supportive warnings, and 2) Finding the best way through the state of flux.

Theme 1 – Supportive warnings

The narratives highlighted the desire to warn other men about the potential thoughts and feelings, during the period, to help to prepare them in a supportive way. These warnings were based on their own experiences, as P1 illustrates how he learnt from his own experience of resisting social support and wanted to warn, and encourage, other men to ask for help:

> *" So I would say to other men, actually its ok to tell other people and ask for help. So it's good to talk, don't bottle it up."* (P1)

The digital narratives highlighted how men's perception of support and its acceptability (including their ideas about what constitutes being 'masculine' or 'manly') have an impact on whether they feel able to cope during the period. As a result, participants were keen to provide supportive warnings – through their digital stories – about important issues relating to coping, encouraging other men to use a range of strategies and acknowledging the need for flexibility and knowing others had 'been there'. P3 uses the term 'brothers' to refer to other men and highlights the importance of speaking up so that other men know that although it may impact their wellbeing, other men have come out the 'other side':

> *"the impact on your body and on your wellbeing, no-one can prepare you for that but if you have a brother or a friend that says, 'yes I've been there, […] that's gonna bring you out the other side […] I found solace'. I joined a group on Facebook and just speaking to others in terms of […] how to use the right words.*

Issues relating to masculinity, help-seeking and support were prevalent and stories recognised that societal expectations or perceptions of masculinity have an effect on an individual's ability to adopt positive coping strategies, as P4's story illustrates:

> *"men, again are reluctant to admit firstly that they feel ill, secondly when they've been told what it is to ask anybody […] they think it's a sign of weakness to ask for help or to say I'm worried about this, it's frightening me, can somebody come and reassure me, because that's not seen to be a manly trait."*

The digital stories encourage other men to find what works for them and encourage an ‘open mind’ and flexibility as the effectiveness of strategies changes over time. The narratives recognised the reluctance to allow the social support network to help initially. Through the reflection process of recording their digital stories, participants recognised their reluctance as a way of trying to keep a sense of control. There was a concern that others may also resist support during the transition, and participants took on a role whereby they exercised their voice to speak up and warn other men:

> *“actually sometimes people would want to help […] I actually don’t allow other people to be that support, even though they might be my close friends because I for all kind of other reasons am quite independent around that sort of thing.” (P1)*

The digital story narratives highlighted the acceptability of experiencing a range of emotions as illustrated by P3’s description of the period as *“like being on a rollercoaster.”* Participants spoke about the effectiveness of adopting a positive outlook during the period, as recognition was given to the impact of negative thoughts on the experience, and the knock-on effect for themselves, friends and families. The narratives across the accounts urged the audience to approach the period mindfully, to deal with each day as it comes, not to think too much into the future or pre-empt outcomes, and deal with the facts and practicalities *“straightaway I’d say, don’t fear the worst because I think you naturally tend to”* (P2).

Theme 2 - Finding the best way through the state of flux

Each participant talked about finding their best way through the period using different strategies:

> *“I think its finding your best way through […] having that supportive network around you […] You will drift once you get your news, or when you’re about to get your news cause you’re in this constant state of flux. And not knowing, will it, won’t it, yay, nay, and someone or the support you have from your own family keeps you grounded cause then you’re focus is on maintaining a good family relationship with everybody, irrespective of your fears and that helps to keep both feet on the ground.”* (P3)

P3 refers specifically to the family support as giving stability and grounding him during a time of uncertainty. The men identified the four coping strategies they deemed to be most effective: the use of a social support network; distraction; physical activity, and; planning and preparation. The use of a social support network consisting of trusted others, made up of primarily family and friends, and the use of peer support were also cited. The support described was generally on a one-to-one basis and the details or functions of the support varied. With family and friends, value was placed on the 'normality' that the network gave men during a time of uncertainty.

Whereas with peers, it was learning and gaining insight into their experiences and the provision of hope for the future, as P2 describes:

> *"Hearing from other people's experiences in terms of coping was quite useful. My wife is a School Teacher and she had many of her colleagues, perhaps three or four who'd had husbands go through similar things so I was able to get quite a wide range of their experiences really. I mean some were mildly affected by the Cancer. Others had some had got pretty bad situations but it gave me some sort of insight as to what was actually happening to them. I didn't do a lot of talking to too many people."*

The use of physical activity was prevalent across the stories and recognised as an effective strategy, with a range of benefits such as improved physical and mental wellbeing, distraction, and a social support function. This included both group activities such as basketball, and solo activities such as walking in green spaces. P3 illustrates his experience:

> *"basketball was very important. I've been involved in basketball for, it's over 40 years. Playing, coaching and then refereeing. […] it's about maintaining normality. My thing is my basketball and one it helps keep the weight down and two it's another social circle with like minded people who love sport and three, it gives you space as well if you want to just disappear from that internal pressure you feel awaiting your diagnosis so it's good to keep up with what you're doing"* (P3)

Across the digital stories, the opportunities physical activity created to alleviate the pressure during the waiting period was felt to be positive. The ability to use distraction as a coping mechanism was also favoured, with keeping busy at work cited as a valuable tool. The stories described the value in the opportunities that distraction presented for reflection, in addition to the suppression of emotions. Any activity that enabled concentration, eliminating space for negative thoughts, supported the ability to manage whilst waiting for confirmation of the cancer test results. As P3 described above, with reference to basketball, the importance of keeping up with 'normality' was valued: this mainly included work, hobbies and household or family duties. Recognition was given to the effects of not using this strategy and the potential for forecasting and rumination, "*and if you haven't got something, find something to help you manage your time rather than sitting alone and then start to over worry about what might or might not happen"* (P3).

The ability to take action, through planning and preparation, facilitated the opportunity to focus and concentrate on an activity that was concrete and practical, which was favoured. The digital stories expressed the sense of control that having the ability to be 'doing something' gave them whilst waiting. Planning covered a range of topics, including identifying the next steps and reflecting on options for the future such as early retirement. P1 talks about how planning was key for him:

> *"thinking about what's important to me things like planning and managing stuff is really important. So with whatever is happening for me, I need to know what the next steps are. I need to know what's going to happen, when is it going to happen and how am I going to manage it. I mean even in my work life there's stuff, you know, there's always a sense for me of wanting to see things through to the end so I would want to know what's going to happen next so I can finish what I need to finish or when I'm going to finish or how I'm going to do it."*

Stage 2 – results

Questionnaire findings - evaluation of the digital story making process

Three themes emerged from the questionnaire feedback men gave about taking part in the DST process: 1) Giving back; 2) Adding value and greater impact; 3) Therapeutic benefits.

Theme 1: Giving back

> *"I wanted to give something back and […] hoped what I had to say could be of help to other people in same position as I was"* (P4)

The main reason given, when participants were deciding whether to be involved with the project, was to give something back to benefit other men in similar circumstances, to help make the waiting period a better experience:

> *"I thought that it might be useful to others experiencing a similar situation. I was becoming aware […] the number of people who were being diagnosed and […] heard of a few individuals who had been diagnosed quite late."* (P2)
>
> *"I thought it would be good to share the experience with other(s) so that it might help to make the experience better for others through the research being undertaken."* (P1)

Participants acknowledged the struggle men face with talking about their health. This recognition strengthened the desire to give back to other men to provide support. In reflection, P3 talked about acknowledging his obligation to contribute positively to support the struggle men face as part of a wider societal issue:

> *(P3) I decided to participate because I felt a moral obligation to. All men struggle talking about their health, especially to partners, wives, family and friend. My post op success made me want to actively contribute to supporting others to really understand what goes on in a man's head with such a serious prognosis. "It's a man thing"*

The experience of making and viewing the digital stories created mixed emotions for participants. At times participants reported feeling uncomfortable because they were not keen on seeing or hearing themselves on screen. However, part of 'giving back' was the motivating factor to contribute, illustrated through their willingness to put their own feelings aside for the greater benefit of being involved to help others:

> *"weird watching myself, looks ok, I seemed a bit repetitive at times but happy with what I was trying to get across. Hope it's useful to other people"* (P4)
>
> *"Never like looking or hearing my voice on tape or camera"* (P1)

Theme 2: Adding value and greater impact

> *"it adds value as […] better to hear from personal experience than from someone who has learnt from other people. More of an impact [...] great feelings of 'this is for real'"* (P4)

The opportunity to talk about personal experiences from a man's perspective to another man, communicating peer support and empathy, was felt to be particularly valuable and provide a greater impact (than more traditional methods). They described them as adding value by offering something extra, a different dimension, to the usual methods of information provision (for example, through leaflets or conversation with healthcare professionals). The supplementary nature of digital stories was felt to be beneficial to the retention of information and had multiple uses:

> *"you can only get so much from reading pamphlets […] or the Internet. Health professionals are extremely good in explaining what is happening but it doesn't sink in too well after initial diagnosis and therefore such films and information are good back up to these conversations"* (P2)

> *“with social media gaining such a strong place in our modern way of communicating it is good to have films that help to shed light on this area. I know that this is not everyone’s learning style so the good thing about this sort of resource is that it can be used by an individual in their own space and in their own time or be used with a group etc. to help learning”* (P1)

There was also the recognition of the reality of the experience, connecting with the raw facts, which was enabled through the digital storytelling approach:

> *“I think this is one of the best mediums to engage with men. There's something about “telling it as it is” from a male perspective. Most men don't like things sugar coated.”* (P3)

Participants wanted to add value to other men’s experiences through communicating the effective strategies they had used to cope. There were several convergent themes that spanned across the accounts defining men’s experiences, detailing the strategies they used to cope and the effectiveness of each. As participants had been through a previous telephone interview with the researcher, for a previous qualitative study, they were able to compare the approaches. Participants reported that the process added value in comparison to telephone interviews alone, bringing authenticity. The workshop presented an opportunity to interact and meet face-to-face, which was reported as beneficial, more engaging and impactful:

> *“more nervous on the film as I knew I was being recorded and did not want to sound muddled however after a little while into the process I forgot the camera was there”* (P1)
>
> *“far more engaging. Once I got over the camera being in the room, I enjoyed the experience.”* (P3)

Theme 3: Therapeutic benefits for storytellers

> *“It helped to talk about my experience and […] was therapeutic […] enjoyable and cathartic”* (P2)
>
> *“A greater understanding of my own feelings […] helped me get my head around my feelings. Good therapy…”* (P4)

Participants spoke about the therapeutic benefits they had gained from being involved with the digital story process. The main benefit cited was the opportunity to ‘open up’, understand and ‘make sense’ of their own feelings through a therapeutic effect of the process of digital storytelling. The reflective process gave participants’ permission to ‘value’ their experiences. By hearing them out loud, participants acknowledged the ‘shift’ in thinking that the process of digital story telling had provided, which resulted in helping to think about the experience in a different way, providing new insight:

> *“Funny it was sort of cathartic […] helped me make sense of it. The questioning was sensitive and allowed me to open up […] Insight into what I felt about the experience and if I was to face it again, it would help me to think differently about it.”* (P1)
>
> *“I learnt to be more open about my journey or maybe that was because someone was interested in my journey beyond the usual “thank god you're ok now” which is when the conversation normally ends”* (P3)

Discussion

The aim of this study was to develop digital stories for unheard voices and evaluate the digital storytelling process to co-design narratives with men about the cancer early detection period. The creation of four digital stories has been an integral part of this study and the findings suggest that the process involved with developing digital stories can lead to articulation and transformation of the experiences in several ways. Overall, participants identified: several key messages to communicate to other men to aid coping; and reported benefit-finding through the therapeutic process, with psychological relief from the open expression of emotions. These findings resonate with the notion that digital stories offer an opportunity to understand and connect with an experience rather than simply explaining it providing benefits, to not only the audience, but also the individual storytellers.

Increasing the involvement of people affected by cancer in the development of support interventions is imperative, given the improvements in decision-making, communication and better health outcomes involvement provides (Crawford et al., 2002). Over recent years, health policies in the UK, and internationally, have aimed to increase engagement and patient participation (Crawford et al., 2002; Department of Health 2005; Wilcock et al., 2003; World Health Organisation, 2016). However, there is an assumption in research that men do not participate in creative activities (Hammond et al., 2018), with male representation in creative interventions scarce (Geue et al., 2010; Saunders, Hammond, & Thomas, 2018). The reason for the lower participation remains unclear and has been prioritised as a topic for further investigation of its own (Geue et al., 2010; Hammond et al., 2018). It could be suggested that the findings from this study provide evidence, and an innovative example, of the benefits of involving men in the development of potential creative solutions. The findings suggest that a process of co-designing and creating digital stories might be an acceptable mechanism for men to highlight the psychosocial impact of cancer, for the benefit of others. They provide a forum for health care professionals and other researchers to understand the impact and distress of the cancer early detection period with men. Using user-led co-design principles, this study has utilised participatory design techniques (Bason, 2010; Bate & Robert, 2007; Parker & Heapy, 2006; Voorberg, Bekkers, & Tummers, 2015) based on a parity of esteem between participants and the researcher, with mutual respect for reflexivity and fluidity. Therefore, it could be suggested that this study adds to the case for change in dispelling the assumption that men do not participate in creative activities (Geue et al., 2010; Hammond et al., 2018) and contributes to the field exploring men's experiences of engaging with arts-based approaches within the field of cancer (Saunders, Hammond, & Thomas, 2018). Nevertheless, using DST requires substantial investment of resources in terms of training and costs associated with obtaining, and using, audio-visual and IT equipment. Therefore, this might limit and prohibit its widespread usage.

The study highlighted the acknowledgment given to the limitations of traditional information and support resources during times of distress (such as issues with recall and retention). Participants recognised the value of the multifaceted nature of digital stories in the ability to engage audiences in a unique way – reinforcing information and messages – by visual and auditory learning. Illustrated by Participant P1's description, participants believed that digital stories provide a "back up", creating a safety net to aid understanding and retention of information about expectations during the period. The threat of a life-altering illness such as cancer can disorient and overwhelm an individual (Hovey & Paul, 2007) with additional heightened emotions (fear, anxiety and uncertainty) which may impact and interfere with the processing of health information (Zeliadt et al., 2006). Studies have found that the ability to learn, for individuals in distress, is compromised as the distress interferes with the individual's ability to take on board new information or complex knowledge (Castles, 2004; Merriam, Caffarella, & Baumgartner, 2002; Willans & Seary, 2007). Individuals with poor literacy benefit from information presented digitally (Birru et al., 2004). However, despite the perceived value of the method, the expectation, participation and skill level of participants may impose limitations on the extent of the use of DST. As the process involves the co-creation of stories using digital equipment, there is a need for participants to have, at least, a basic level of IT understanding and this requirement may prohibit and restrict the engagement of some participants. Nevertheless, this study provides some evidence of the added value that the approach could provide future individuals with, and it could be argued that the absence of a physical presence with others makes it less difficult to discuss burdensome topics (Høybye, Johansen, & Tjørnhøj-Thomsen, 2005), leading to the articulation and transformation of illness experiences through a space for reflection and recognition of thoughts.

Issues relating to masculinity, help-seeking and support were prevalent across the digital stories. In relation to the transactional theory of stress and coping (Lazarus, 1999; Lazarus & Folkman, 1984), the digital narratives highlighted how cognitive appraisals (such as the perception and acceptability of support in relation to masculine ideals), and the coping strategies employed, impacted on experiences and outcomes. The cancer early detection period was recalled as a time of uncertainty, and methods of coping were described as fundamentally interpersonal in nature, and used as a mechanism to adapt, switching between problem-focused and emotion-focused strategies. In response, messages urged the listener to be flexible and use a range of effective coping strategies, to provide stability and grounding during the time of *'flux'* (P3). Participants recognised, through reflection, how an attempt to keep 'a sense of control' (by distancing from their social support network) impacted negatively on their experience. Through reflection, that others may also resist social support during the transition, participants used their voice to warn other men about the potential pitfalls while supporting them by sharing experiential knowledge to promote well-being for all (Broom, 2005; Sillence & Mo, 2014). This finding corroborates with other studies, in the field of cancer genetics, with individuals facing the prospect of cancer who wanted the opportunity to listen to other individuals' similar experiences to gain a better understanding of the processes involved and help to manage expectations (Iredale, Gray, & Murtagh, 2002; Phelps et al., 2007). Consequently, providing people affected by cancer with the information they need in an accessible and engaging format helps individuals to prepare and cope during the period (Iredale, Gray, & Murtagh, 2002; Metcalfe et al., 2009; Phelps et al., 2007). Therefore, it could be suggested that by providing digital stories from men who have experienced the cancer early detection period, talking about what strategies they used to cope with the emotional challenges, men in the future may benefit as they wait to find out if they have cancer or not.

The findings identified a key motivator for participation, described as a *'moral obligation'* (P3), as the need to inform and protect other men. It could be suggested that the opportunity and space for reflection that digital stories provide benefits peers through the 'expert by experience'. This finding is important because accrual of knowledge and expertise has been linked with associated benefit to men's self-identity and self-esteem after a cancer detection (Bell et al., 2010; Bourke et al., 2012; Broom, 2005; Dickerson et al., 2011; Oliffe et al., 2010; Sullivan, 2003; Trapp et al., 2013). This aligns with studies involving men with long-term conditions, and identifies with the construct of ‘becoming an expert’ (Galdas et al., 2014). Considering this alignment and proposed association with self-identity and self-esteem, careful planning needs to be conducted to provide the optimal conditions for facilitating the reflective approach needed for DST. The availability and accessibility of resources in addition to practical requirements should be considered, such as: an accessible private space to conduct the workshops; the portability of the audio-visual equipment; and the human resource (expertise with editing and production). Additional human resource requirements may also be needed to facilitate digital story workshops, and the production process, with experienced and skilled personnel. Without careful consideration of these factors, there might be potential risks to the quality of the process and the significance of the outcomes.

The opportunity to co-design digital stories for future men was a strong motivator for participants’ involvement, the opportunity to ‘give back’ was another driving force for being involved. Recognition was given to the opportunity to voice experiences, choose the narrative and select the elements to tell. Even when the process involved experiencing feelings of discomfort (such as having to watch the stories back), there was willingness to overcome feelings for the benefit of others. Thus, it could be argued that the stories act as resources to help individuals form and illustrate their identity, giving others a sense of who they are: this finding is in keeping with previous wider research (Schiffrin, 1996; Wortham, 2000). Other studies of digital storytelling have reported several positive benefits including, amongst others, increases in self-efficacy (Esterling et al., 1999; Gortner, Rude and Pennebaker, 2006; Pennebaker, 2000). Meaningful activities give support to men with cancer (Morrison & Thomas, 2015). Therefore, it could be suggested that by framing support as ‘helping others’ or illustrating a clear link to facilitating ‘productivity’, men may be more willing to accept help themselves. This link corroborates with wider studies outlining how giving back is important for male identity and self-esteem (Cramer et al., 2014; Galdas et al., 2014; Gray et al., 1996; Oliffe et al., 2008; Seymore-Smith, 2008). The opportunity to help others and ‘give back’ are important considerations for future intervention development as recent studies (Campbell et al., 2012; Hoyt et al., 2013) have found that men who feel that they retain control over their environments experience less conflict in their beliefs about masculinity. The ability to be independent, feel in control and confident are all aspects that determine outcomes in relation to the ability to cope and have a good quality of life for people affected by cancer (Foster et al., 2015; Mertens et al., 2012; Raaijmakers, 2014; Sloan, Padrón, & Platt, 2009; Waller & Pattison, 2013; Wenger & Oliffe, 2014).

Strengths and limitations

This study is the first of its kind, specifically with men, during the cancer early detection period. A strength of this study is the different approach it offers through the medium of digital stories, using images and voices of experience to communicate messages in a meaningful and engaging form. This approach makes a positive contribution to the lack of current resources available to men within the cancer early detection period. It is recognised that emotional or embodied ways of knowing are often dismissed, as they produce less robust data that can be tested objectively (Foster, 2012). However, Boydell et al. (2012) highlight the powerful shared space that qualitative research has with arts-based research to illustrate the subjective nature of human experiences.

There are several limitations to the study. While there is a literature showing that research practices such as digital stories can be beneficial to the health of participants (Ferrari, Rice, & McKenzie, 2015), and the participants themselves spoke of the therapeutic effect, there are also limitations to the approach. The process of inviting participants to think back to a time that may have been distressing, and encouraging them to discuss and engage with the experience, may have evoked painful memories.

Although a purposive sampling method was used for the study, it is possible that selection bias was introduced into the study as participants had already expressed an active interest in providing support to other men. It should be acknowledged that the study participant sample consisted of those who were comfortable with telling their story and participating in a participatory workshop. It is recognised that the use of a different method to co-create the stories and communicate the experiences of the period may have resulted in a different type of relationship between the researcher and participants, impacting on the findings. Therefore, potential bias and interpretation of the findings must be carefully considered, given that this study recruited participants who had previously expressed effective coping strategies (during the interview in Chapter 3). In addition, the cohort consisted mainly of individuals who went on to receive a diagnosis of cancer and thus not necessarily representative of men undergoing testing within the general population. However, this is not explicitly clear to the viewer, and the research was to understand from men who have been through the testing period, not whether they went onto receive a diagnosis or not. Another limitation is that the time since experiencing the cancer early detection period varied, and therefore recall may have been an issue for some study participants. However, all of the participants had received a diagnosis within the last 2.5 years and so had recent experience. It is recognised that there are limitations to qualitative research in changing health practices (Ziebland & Wyke, 2012), and the evidence base to support visual interventions, and digital stories in particular, is still growing.

It could be argued that as the study was qualitative in nature, a better understanding of certain phenomena related to men's experiences of the early cancer detection period was achieved. However, the themes identified must be read in the context of the small sample and the lack of diversity within it may have limited a deeper understanding of men from different sociodemographic or ethnic profiles. Caution needs to be taken in generalising the findings of this study to wider groups of the population.

Implications

Through a unique qualitative methodological participatory action research approach, this chapter has outlined the development of digital stories for future men to access to understand the experiences of other men during the cancer early detection period. The digital stories are a resource that will enable the transfer of knowledge between peers, as a standalone resource or embedded within a wider online intervention.

Within the digital story literature, the neutrality of the researcher and their role within the process of DST, have been questioned. Demonstrating rigour within qualitative research can achieved by evaluating the trustworthiness of the research process. Guba and Lincoln (1989) propose that in order to ensure trustworthiness of the research process, four criteria should be satisfied, including: credibility, transferability, dependability, and confirmability. Future DST researchers must build in, and report on, procedural rigor to establish the 'trustworthiness' of findings (Creswell, 1998; Erlandson et al., 1993; Lincoln and Guba, 1985). This can be incorporated into DST methodology in a variety of ways, including: reflexive journaling; member checking and verification (Rager; 2005); thick description of the research context, multiple reviewers at each level of analysis, and descriptive field notes (Eakin and Mykalovskiy, 2003; Rager; 2005).

The digital stories could easily be integrated into the wider online intervention. The online delivery of the intervention offers scope to integrate these experiences and highlight the social support element through the creative method. This study offers some promise and opportunity to address specific needs within an understudied area of research.

Conclusion

The cancer early detection period is a time of disruption for many men and, given their underlying emotional state, communication around the time of a diagnosis of cancer is fraught with difficulties and tensions. The findings from this study demonstrated that the process of co-designing digital stories is an acceptable mechanism for men to highlight the psychosocial impact of the cancer early detection period. Through the user-led co-design of the digital stories, the therapeutic benefit of reflection has been activated giving voice to the men's interpretation and perceived meaning of their experiences. Facilitated through the multi-sensorial nature, it could be argued that digital stories have provided insight into the experience of the individual storyteller at a far deeper level than is possible through text alone. This study has highlighted the opportunities of using visual media to engage men in groups for whom in person face-to-face health-related information may be more challenging.

This study offers one possible solution to the identified need for peer support during the time-limited period of the cancer early detection period. This study is thought to be the first of its kind to use digital stories to illustrate the experiences of men during the cancer early detection period for any cancer type. The digital stories provide a set of rich examples of experiential knowledge, with scope to further develop and test the applicability and usability of the digital stories with future men during the cancer early detection period.

Chapter 6 – Development of an online intervention for men during the cancer early detection period: *Men in Limbo*

Introduction

The previous chapter highlighted the value of an arts-based approach to conducting research, through the user-led co-design of four peer digital stories, and found several benefits for both the storyteller and audience. The chapter described the opportunity of using visual media to engage men in groups for whom in person face-to-face health-related information may be more challenging. Evidence suggests that men with cancer are choosing to access support remotely or using self-directed approaches (Beatty, Koczwara, & Wade, 2011; Duffecy et al., 2013; Leykin et al., 2012; van den Berg et al., 2013) and when experiencing high levels of distress, preference is given for help to access support independently to effectively manage by themselves (Clover et al., 2015; Neumann et al., 2010). The digital stories provided a set of rich examples of experiential knowledge and one possible solution to the identified need to access peer support independently during the time-limited cancer early detection period. However, the chapter recognised the limitations of digital stories and the requirement to provide further support to address the other unmet needs identified in Chapters 3 and 4 of this thesis.

The recognition in Chapter 5 of the need for further support (and the potential to engage men through digital communities) determined the focus for this current chapter. In other supportive forums (such as online self-management support), men place value on having the option to be present, but also listen without the expectation to contribute, offering opportunities for individuals that would not be possible offline (Allen et al., 2016). Other studies have shown that by giving men an element of control over the extent of their involvement, with support interventions (Oliffe et al., 2010; Sandstrom, 1996), can increase their acceptability. The ease of access and anonymity of gaining support, with equitable outcomes to traditional face-to-face delivery, provide an opportunity for technology-based interventions to reach populations that might not engage with traditional health or support services, overcoming barriers to uptake of support such as isolation and stigma (Nanton et al., 2018). Digital social communities with peer support can improve illness experiences and may offer opportunities for individuals that would not be possible offline (Allen et al., 2016). Online interventions offer a cost-effective alternative to face-to-face interventions and minimise the stigma of help-seeking for men after a cancer diagnosis (Wootten et al., 2014), offering anonymity and accessibility at any time. Recent research suggests that online interventions focused on changing behaviour are likely to be more effective when they are co-designed with users and appeal to the target audience (Ellis et al., 2012; 2013). Therefore, building on the findings from the review of the literature and the empirical studies detailing unmet needs, the aim of this chapter is to outline the development of an online intervention targeted at supporting men to enable them to cope and manage distress effectively during the cancer early detection period.

With cancer incidence rates rising (Smittenaar et al., 2016), there is a growing need to detect cancers early, before they metastasise to other organs, as late diagnosis is associated with lower survival, increased morbidity, poorer outcomes (Department of Health, 2011a; NCSI, 2013), and increased costs (Department of Health, 2011b; Incisive Health, 2014).Detecting cancer early has been a goal of cancer research for many years and although recognised as a time of uncertainty and fluctuating levels of distress, there is limited research that identifies the support needs of men during the cancer early detection period (Irving, 2001; Lang, Berbaum, & Lutgendorf, 2009). Therefore, the exploratory work in this thesis aimed to identify and understand more comprehensively the experiences and support needs of men during the period to inform the development of an appropriate online self-management support intervention. This research has been underpinned by the MRC framework for developing and evaluating complex interventions (Craig et al., 2008) and the Transactional Model of Stress and Coping (TMSC) (Lazarus, 1999; Lazarus & Folkman, 1984).

The MRC Framework stipulates that interventions based in theory are considered to be more robust, as they target determinants of behaviour and lead to improvements in outcomes (Craig et al., 2008). Used extensively in intervention research, theory driven design has been used to inform the specific components of proposed interventions (Davies, Walker and Grimshaw, 2010). Effective outcomes and increased adherence to advice have been found in studies that are based in theory than those without (Craig et al., 2008; Carnes et al., 2012).

The Transactional Model (Lazarus, 1999; Lazarus & Folkman, 1984) has been used as a theoretical basis throughout the studies in this thesis, as it has with other studies on cancer (Garrett et al., 2013; Halstead & Fernsler, 1994; Parle & Maguire, 1995; Reynolds et al., 2000). The model includes the individual’s process of cognitive appraisal of the situation, the coping strategies used and the outcomes for those experiencing the stress. Research in the cancer field makes connections between emotional (Costanzo et al., 2005; Longman, Braden, & Mishel, 1999) and cognitive (Jenkins & Paragament, 1988; Burgess & Haaga, 1998) adjustment and readjustment, aligning with psychosocial outcomes. Men during the early detection of period of cancer undergo exploratory procedures and consequently emotional adaptation and re-adaption, and therefore the model was chosen to incorporate the special conditions involved with men waiting for cancer test results. Used widely in health research, and more recently in intervention design, the transactional model offers a generic framework for adaption and coping, with a valuable empirical foundation (Garrett et al., 2013; Halstead & Fernsler, 1994; Parle & Maguire, 1995; Reynolds et al., 2000). In accordance with the model, a combined variation in cognitive appraisal, emotion and coping responses formulated individual differences in outcome to perceived stressful events (Lazarus, 1999).

Previous research applying the model to the early detection period of cancer has evidenced the importance of the Transactional Model components in predicting and testing psychosocial outcome, especially cognitions (Hulbert-Williams et al., 2013). Therefore, considering stress processes are transactional, and coping outcome is linked to both cognitive appraisal of the stress event and emotional responses, the proposed intervention underpinned by the transactional model, incorporates intervention components that correlate with the model's processes. Studies from the psycho-oncological field have reported the potential for positive changes and growth as a result of experiencing challenging life events (Scrignaro, Barni, & Magrin, 2011; Stanton, Bower, & Low, 2006). As personal growth and positive cognitive revisions are also potential consequences of distress (Miles et al., 1999), a threat of cancer has the potential to stimulate positive psychological changes in an individual's self-perception, social relationships and priorities (Calhoun & Tedeschi, 2006; Joseph & Linley, 2005, 2008; Tedeschi & Calhoun, 1996). Subsequently, the incorporation of techniques and intervention components aimed at supporting cognitive appraisal, emotion management and coping are fundamental to the proposed intervention developed to support individuals to self-manage during the early cancer detection period facing a potential cancer diagnosis. These include: intervention components centred on CBT and cognitive reframing (of feelings and thoughts); developing coping strategies; and peer support have been built in to the intervention. Taking these considerations into account the intervention has built-in flexibly to: meet the specific type of adjustment difficulties presented; and provide 24/7 accessibility, to meet the individuals identified needs (with a pick and mix approach).

Aim

The aim of this study is to identify the evidence that supports the content of an online intervention for men during the cancer early detection period. The study aims to answer this research question:

What is the evidence to support the content of an online intervention for men during the cancer early detection period?

Designing and developing effective interventions

There are a variety of frameworks used to support the systematic process of intervention design and development. Recognised since the 1990s, to improve the chances of successful outcomes, the development of effective interventions should be carried out systematically (Brug, Oenema, & Ferreira, 2005; Kelly & Kalichman, 2002; Kok, Van den Borne & Mullen; 1997; Mullen, Green, & Persinger, 1985), based on evidence and theory (Green & Kreuter, 2005). To support the systematic process of intervention development for this study, a variety of frameworks were considered, including: Intervention Mapping (IM) (Bartholomew et al., 2011) and the Capability Opportunity Motivation and Behaviour model (COM-B model) (Michie, van Stralen, & West, 2011).

Used by intervention developers across the world, intervention mapping (IM) uses a six-step framework to support the development of behaviour change interventions, by the systematic application of behavioural science and social theory (Bartholomew et al., 2016). Each step is made up of several tasks - and each completed task is collated to inform the next step – developing a ‘map’ for the design, implementation and evaluation of a proposed intervention. The first stage provides the context by describing the problem, identifying the needs and constructing a logical model, detailing the wider environmental and behavioural factors causing the problem. Step 2 entails producing a matrix of change objectives. The third step involves identifying the theory-based change methods and practical applications to be applied, and in Step 4 programme components and materials are produced. The final parts include Step 5, which plans out the programme’s feasibility, adoption and implementation. Finally, in Step 6, a plan for evaluation is produced. There are numerous beneficial outcomes associated with developing interventions using IM. For example, Michie et al.’s (2008) systematic review showed a marked difference between interventions developed using IM compared to placebo control groups with regards to uptake of disease prevention behaviours.

The NICE guidance (2014) on individual approaches to behaviour change outlines that behaviour comes about from an interaction between an individual's 'capability' to perform a behaviour, and the 'opportunity' and 'motivation' to carry it out. A change in one of these components is needed to create either a change in behaviour or new behaviour. The Capability Opportunity Motivation and Behaviour model (COM-B model) is widely used to understand the fundamental conditions that must be understood before the development of effective interventions (Michie, van Stralen, & West, 2011). It provides a broad 'behaviour system' that provides a structure for assessing capabilities, opportunities and motivations. The COM-B Model is at the hub of the Behaviour Change Wheel (BCW) framework, and is a central component, which has nine intervention functions that feature around the hub. The surrounding functions fulfil the identified gaps in capabilities, opportunities and motivations that are suggested to lead to changes in behaviour (Michie, van Stralen, & West, 2011; SAL M & West 2014). It could be suggested that the models use of accessible language makes it more engaging, and less prohibitive, to non-academic audiences (such as patients) enhancing its applicability to real-world contexts (Desveaux et al., 2019). There are numerous benefits to the model including its: provision of a comprehensive framework enabling the systematic linkage of barriers to change to evidence-based intervention strategies (Michie, van Stralen, & West, 2011); and its ability to enable interventions to be designed with the target behaviour in context. However, when using the model to build self-management support interventions its inability to include the broader services required to deliver self-management support presents limitations (Pearce et al., 2015).

When chossing the framework for developing the intervention outlined in this chapter, a number of considerations were taken into account. The approach needed to be flexible enough to allow for intervention development in a systematic way, taking into account the wider considerations of self-management support, and to be able to use the findings from the rich empirical studies conducted, underpinned by the Transactional Model of Stress and Coping (Lazarus, 1999; Lazarus & Folkman, 1984)). When comparing and considering the frameworks, both IM and the COM-B model approaches appeared to provide an effective systematic way to build the intervention to produce a theory-driven evidence-based effective intervention to support men. However, within both the COM-B model and IM frameworks, the ability to map behaviour change techniques involves knowing which behaviour the intervention is targeting and aiming to change. This presented a limitation to the proposed development of the intervention process. The difference within self-management support is that it is not always possible to map behaviours as it is more commonly about patient activation - providing people with knowledge, skills and confidence to manage their condition (Hibbard & Gilburt, 2014) - than identifying behaviour (Pearce et al., 2015). Self-management support interventions are aimed at outcomes much wider than changing an individual's behaviour. In recognition of this limitation, and the need for an iterative intervention that would provide men with the knowledge, skills and confidence to manage, other approaches needed to be considered.

Whilst scoping the approaches to identify a comprehensive systematic framework to develop and design the intervention outlined in this chapter, the Practical Systematic Review of Self-Management Support for long-term conditions (PRISMS) taxonomy of self-management support (Pearce et al., 2015) and Template for Intervention Description and Replication (TIDieR) checklist were identified. The appeal of the frameworks, for the purposes of the study, were their ability to characterise all the potential components of self-management support interventions, taking into account the wider self-management support considerations (Pearce et al., 2015).

The development of *Men in Limbo* and contributing evidence

The low quality of reporting interventions (Hoffmann et al., 2014) results in a lack of properly defined interventions and the inability to build on previous research (Hoffmann, Erueti, & Glasziou, 2013) or collate a robust synthesis of evidence (Cook, Douet, & Boutron, 2013; Michie et al., 2013). To ensure effective comprehension and clarity of the proposed online intervention, and its components, two evidence-based tools have been chosen to illustrate the specific details. The first is the Template for Intervention Description and Replication (TIDieR) checklist – and guides – which provide a robust framework for ensuring that interventions are reported systematically and transparently (Hoffmann et al., 2014). The purpose of the TIDieR checklist is to ensure interventions are described in sufficient detail to allow for their replication and extension by others, facilitating a complete published comprehensive description of the intervention (Hoffmann et al., 2014). To ensure the reliability of intervention implementation, key features such as duration, mode of delivery, and monitoring all need to be detailed explicitly, as they influence replicability and efficacy (Hoffmann et al., 2014). The checklist details the minimum recommended items for outlining and describing an intervention comprehensively in recognition that interventions with clearly reported guidelines provide and enable researchers, editors and publishers to describe transparently the content, process and outcomes (Turner et al., 2012). The comprehensive reporting of interventions will assist with providing clarity, increasing the repeatability of the research (Chalmers & Glasziou, 2009; Glasziou et al., 2014) and has the potential to increase the impact of research on health (Hoffmann et al., 2014). Therefore, this approach gives a greater assurance for future transferability and replicability. Table 17 outlines the proposed intervention using the TIDierR tools (Hoffmann et al., 2014).

This comprehensive description of the intervention, as outlined by the TIDieR checklist in Table 17, details how each chapter within the thesis contributed evidence to develop the content of the online intervention. Chapter 1 provides evidence of the prevalence of fluctuating distress in men across cancer early detection period studies (Cormier et al., 2002; Dale et al., 2005; Dillard et al., 2017; Gustafsson et al., 1995; Medd et al., 2005; Ng et al., 2013; Roumier et al., 2004). Stress-related reactions, and anxiety, have been found increasingly in people during the cancer early detection period (Awsare et al., 2008; Lu et al., 2016). The chapter's findings provide evidence for the development of support management of thoughts, and emotions, and self-management exercises to aid coping (including mindfulness and relaxation, goal setting) and positive psychology tools (including gratitude exercises and recognising strengths-based exercises). The mixed methods systematic review in Chapter 2 provided evidence in support of information, education and support before detection to help men to prepare, and manage expectations about the processes and procedures, during the cancer early detection period (and reduce the anxiety experienced). This review concluded that interventions introduced during the period do not cause anxiety and can prepare men for diagnosis and reduce anxiety. Health education interventions provided effective knowledge for those who go on to receive a diagnosis of cancer, and can engage, prepare and inform men to manage uncertainty (Chiu et al., 2016; Wade et al., 2015 Zeliadt et al., 2013). The review highlighted the need for more empirical research to be able to identify and prioritise the needs of men, and their subjective experiences, during the period of uncertainty.

The findings presented in Chapter 3, highlighted the range of common shared psychosocial needs and experiences, and specific unmet needs for: isolated men; navigation to credible tailored information sources; connectivity with other men's experiences, and; emotion management. The findings evidence the use of the internet as a useful tool to gain information and knowledge during the period, and highlighted it as the *"first port of call"*. The review confirmed that no evidence-based online peer support, self-management intervention currently exists for men to access during the cancer early detection period, highlighting a gap in current provision and opportunity for intervention to address unmet needs. Chapter 4 findings identified the greatest needs related to: the ability to plan; having effective communications with healthcare professionals; accessing social support, and; accruing information and knowledge. Participants placed high value on social support, with the beneficial impact of having a supportive individual and learning from peers' experiences who provided emotional support to cope and manage thoughts, feelings and uncertainty. The findings from the qualitative studies in Chapters 3 and 4 provide evidence for the impact and value of social connectivity, as men suggested that being connected was related to better management of emotions and perceived ability to cope effectively. A supportive individual alleviated distress, and peer support improved confidence and gave reassurance. Evidence, from men's accounts, highlight the coping mechanisms used (problem-focused and emotion-focused) supported the adaption to the threat of illness, helping to alleviate the anxiety experienced.

The findings from Chapter 5 provide evidence of the acceptability and therapeutic benefit of reflection activated through giving voice to men's interpretation and perceived meaning of their experiences. A sense of responsibility motivated the men to 'give back' for other men's benefit (even forsaking emotions such as embarrassment), and digital stories were valued for the opportunity to understand and connect with an experience rather than simply explaining it, giving greater impact. The study led to the articulation, and transformation, of the cancer early detection period experiences, as participants were keen to communicate supportive warnings to other men whilst encouraging them to find the best way through the state of flux. This study strengthens the argument for using visual media to engage men in groups for whom in-person face-to-face health related information may be more challenging. The PRISMS taxonomy of self-management support (Pearce et al., 2015) is the second framework used to illustrate the intervention components. It builds on the Template for Intervention Description and Replication (TIDieR) checklist.

Table 17 TIDieR (Template for Intervention Description and Replication) checklist outlining the proposed online intervention

TIDier item	Item	Evidence	Specific evidence from empirical studies
Brief name	Men in Limbo (online)	Findings from: • Chapter 2 evidenced no online intervention for men undergoing the cancer early detection period • Chapter 3 findings highlighted that men felt 'in limbo' • Chapter 5 findings - men described being 'in flux'	**Chapter 3 – participant 21:** • The period of time waiting for the results of tests to confirm cancer can be described as being in '*limbo*' (P21), not ill but no longer deemed healthy. They waiver between the potential of illness and anticipate disease whilst being asymptomatic "*it could be something or nothing." (P21).* **Chapter 5 – participant 3:** • *"You will drift once you get your news, or when you're about to get your news cause you're in this constant state of flux. And not knowing, will it, won't it, yay, nay"*
Why (Rationale, theory, goal and essential elements)	For men during the cancer early detection period to support: (1) Planning and preparation (2) Effective communications with HCPs (3) Social support (4) Information and knowledge Improve well-being (by providing hope and fostering a sense of acceptance by others in a similar	• Findings from: • Chapter 2 systematic review chapter • Chapters 3 and 4 interviews with men and prioritisation workshop • Chapter 5 digital stories Evidence from literature within the thesis: 1. Hope (Snyder, 2000) 2. Acceptance (Ashbury et al., 1998; Barlow et al., 2000; Campbell, Phaneuf, & Deane, 2004; Dennis, 2003; Edgar et al., 2003; Gray et al., 1997; Ussher et al., 2006;). 3. Normality (Cramer et al., 2014; Dickerson et al., 2011; Gooden & Winefield, 2007; Oliffe et al., 2010; Sullivan, 2003).	**1. Chapter 3 - Participant 1 – HOPE** • Whereas with peers, it was learning and gaining insight into their experiences and the provision of hope for the future, as P1 describes: *"Hearing from other people's experiences in terms of coping was quite useful. My wife is a School Teacher and she had many of her colleagues, perhaps three or four who'd had husbands go through similar things so I was able to get quite a wide range of their experiences really. I mean some were mildly affected by the Cancer. Others had some had got pretty bad situations but it gave me some sort of insight as to what was actually happening to them.* **2 &3. Chapter 3 – participant 2 - Acceptance** • The change came when he got to the support group and started talking to people and recognising that "*they'd gone through exactly the same experiences".* P2 acknowledged that although everyone does their best to understand it is only *"you"* who can *"really explain how you feel to another guy who has been through what you've been through"* (P2). The support offered by groups provides a sense of belonging and a collective shared understanding around experiences with others with a lived experience 'like them'. **4. Chapter 3 - Participant 10 – Normality** • The use of humour aided camaraderie amongst peers going through the same experience as a way of coping and dealing with the anxiety of waiting often described as *"black humour"* (P10) described as *"terrific".* It provided distraction and a way to

	situation, instil a sense of normalcy and diminished feelings of social isolation Build on and develop effective coping skills	• Transactional model of stress and coping, appraisal, outcomes, coping (Lazarus, 1999; Lazarus & Folkman, 1984).	express and communicate difficulties providing inspiration with peers *“who deal well with problems” (P10).*
What **i. Materials**	Four digital stories of men talking about their experiences of coping during the cancer early detection period	• Chapter 5 – findings from digital stories Evidence from literature within the thesis: 1. Peers communicating hope (Banks-Wallace et al., 2007; Legg et al., 2011; Meyer, Coroiu & Korner, 2015; Moulton et al., 2013; Ussher et al., 2006) 2. Learning from peer’s experiences, gathering tips and information (Hinyard & Kreuter, 2007; Houston et al., 2011; Larkey & Hecht, 2010) 3. Communicating empathy with others (Dunn et al., 2003; Faulkner & Kalathil, 2012)	**1. Chapter 3 – Participant 10 - Peers communicating hope** Several men acknowledged the positive impact of hearing others’ stories as it provided “*relaxation*” (P10), because *“if you understand what’s happening and why it’s bound to help”* (P10). **2. Chapter 5 – Participant 1, 3 & 4 - Learning from peer’s experiences** *(P4) “better to hear from personal experience than from someone who has learnt from other people. More of an impact.”* *(P3) “I think this is one of the best mediums to engage with men. There's something about “telling it as it is” from a male perspective. Most men don't like things sugar coated.”* *(P1) “with social media gaining such a strong place in our modern way of communicating it is good to have films that help to shed light on this area. I know that this is not everyone’s learning style so the good thing about this sort of resource is that it can be used by an individual in their own space and in their own time or be used with a group etc. to help learning”* **3. Chapter 3 - Participant 2 - Communicating empathy with others** The peer learning opportunity presented by support groups enable information to be taken on board in a safe trusted environment and provide an opportunity to share feelings. One participant talked about the positive impact he experienced following a suicidal point when he felt “*I’d rather die”* (P2) and recalled how his “*personality had changed so much”* and how he had to readjust to *“a new me”.*
	Information on managing expectations of cancer early detection period	• Chapter 3 findings Evidence from literature within the thesis: • Knowledge and information (Dickerson et al., 2011; Wiljer et al., 2012, 2013) • Information using plain English (Head et al., 2012; Kazimierczak et	**1. Chapter 2 - Knowledge and information** • Findings revealed that information provision played a key role in determining men’s experiences of having the diagnostic test and how well prepared they were had an influence on their experience and the period afterwards (Chiu et al., 2016; Wade et al., 2015; Zeliadt et al., 2013). **2. Chapter 4 – participant 5 - Knowledge and information** • The need to be informed to be able make decisions was highlighted as important and voiced by participants: *“Between the DRE [digital rectal examination] and going back to being told and all that kind of stuff I spent a lot of time going through and reading up on*

		al., 2013; Martin et al., 2013; McClain, 2012;)	*just about everything I could and so I think I was fairly well prepared […]so when she told me what my score was it was ok for me it wasn’t that stressful because I knew what the outcome for me could be.”* (P5) **3. Chapter 3 – participant 8 -** Information using plain English P8 described frustration and a need for “*lay man’s language”* because *“medical language”* used prohibited understanding with recognition that *“easier words”* would enable individuals to have *“understood it more”.*
	CBT to support management of thoughts and emotions	• Chapter 1 findings Evidence from literature: • CBT (Cockle-Hearne & Faithfull, 2010; Molton et al., 2008; Orom et al., 2015; Penedo et al., 2004; Penedo et al., 2006; Penedo et al., 2007). • Cognitive reframing (Bailey et al., 2004; Mishel et al., 2002; Pascoe & Edvardsson, 2016)	**1. Chapter 3 – Participants 7, 12 & 18 – emotions** Feelings of anxiety and distress were common during the period, this was expressed in different ways such as *“going into a darkened room. And shutting the door…”* (P12). *Feelings were* described as *“Wound up, anxious, depressed” (P18)*, *“apprehensive, worried” (P7)* and *“on a downer”.* **2. Chapter 3 - Participants 7, 8 & 17 – thoughts** The rumination led to further thoughts around questions such as “*what if it was too advanced to be treated”* (P7). It is generally accepted that a diagnosis of cancer is a highly distressing event; the shock and disbelief can have a disabling effect, causing instability and an inability to focus “*can’t believe […] I’ve got Cancer […] I don’t know how I’m gonna cope with it”* (P8). There was recognition of the physical impact described as “*like receiving a punch”* (P17) with the inability to “*focus in a rational way”.* **3. Chapter 3 – Participant 15 – thoughts** Thoughts transitioned between “*wildly optimistic to wildly pessimistic”*
	Signposting information to credible tumour specific charities and websites	• Chapter 3 findings Evidence from literature within the thesis: • Reviewing information found on the Internet (Zeliadt et al., 2013)	**1. Chapter 3 – Participant 21 – accessing credible information** • Understanding where to go to access credible information to enable optimum self-management was another identified area of need, as Participant 21 explained his desire to “*have had some information given me so that I knew what was trustworthy if nothing else”* in addition to support from somebody to “*give you some advice, or just direct you to a couple of decent websites and say ignore the others.”* He was concerned about knowing what was “*reliable and what was not”* at the time. **Chapter 3 – participants 11 & 18:** • Participant’s described the difficulty of assessing what ‘accurate information’ is, as it “*isn’t always possible”* (P11) due to the numerous articles on the internet “*that have little to do with real life”* (P11). They wanted references of *“where you could find the information you need reliably”* (P18). Participants were aware of the potential risks and consequences of gaining information and knowledge that is not credible, and the cost to them emotionally at a vulnerable time.

	Self-management exercises to support coping during the cancer early detection period (including mindfulness and relaxation, goal setting)	• Chapter 1 and chapter 3 findings Evidence from literature within the thesis: • Mindfulness (Chambers et al., 2012; Chambers et al, 2016; Dobkin, 2008; Jain et al., 2007; Lykins & Baer, 2009; McKenzie et al., 2007; Ramel et al., 2004; Victorson et al., 2016) • Problem solving (Mishel et al., 2002) • Relieving uncertainty (Stiegelis et al., 2004) • Developing coping strategies (Legg et al., 2011; Moulton et al., 2013; Ussher et al., 2006)	**Chapter 5 – Participant 2:** • The narratives across the accounts urged the audience to approach the period mindfully. To deal with each day as it comes and not to think too much into the future, to not pre-empt outcomes, but to concentrate on the present day and deal with the facts and practicalities *“straightaway I’d say, don’t fear the worst because I think you naturally tend to”* (P1). **Chapter 3 – Participant 9:** • The notion of planning in steps and stages, with an ending, was felt to be useful to ensure a manageable process, Participant 9 spoke of being “*mindful and broke it down”* and likened it to a pregnancy by having to “*go through a lot of pain and discomfort but the end result will be amazing”.*
	Peer to peer tool to support networking to aid social support	• Chapter 3 and chapter 4 findings Evidence from literature within the thesis: • Control over involvement online (Broom, 2005; Gooden & Winefield, 2007)	**Chapter 3 – Participants 18 & 21:** • Participants didn’t know where to go to access peer support and talk to “*somebody else who’d been through it” (P18)* because *“at the time it seemed like the end of everything.”* and would have been “useful” *(*P21) to talk to somebody or to attend “*group sessions” (*P21)*.* This unmet need was spending *“a huge amount of time going onto the internet.” (P21).* **Chapter 3 – participant 14:** • The opportunity for participants to share with others who have been through a similar experience offered participants a space to think about the next stage and enabled them to think about *“a lift of questions”* (P14) they wanted to ask during the diagnostic consultation “*built up”* from “*different things on the internet”.* **Chapter 3 – participant 16:** • The opportunity for peer support accessed via the internet offers an opportunity to connect with other men in a ‘safe space’, overcoming overt issues of masculine ideals, such as stoicism. Participant 16 talked about the support he gained from “*Checkemlads.com. […] a UK based charity”*, which provided the opportunity to ask “*the silliest question”* because “*everyone that’s on there has suffered testicular cancer”.*

	Positive psychology tools: Gratitude exercise Recognising strengths-based exercises	- Chapter 1 and chapter 5 findings Evidence from literature within the thesis: - Establishing goals (Bandura, 1997; Lorig & Holman, 2003). - Identifying and practicing expressing gratitude (Seligman et al., 2005; Sheldon & Lyubomirsky, 2006) - establishing goals (Green, Oades, & Grant, 2006; Sheldon et al., 2002) - Practising kindness (Otake et al., 2006); - Counting blessings (Emmons & McCullough, 2003; Seligman et al., 2005) - Using personal strengths (Seligman et al., 2005)	**Chapter 5 – participant 1:** - Planning covered a range of topics, including identifying the next steps and reflecting on options for the future such as early retirement. P2 talks about how planning is key for him: *"planning and managing […] is really important. So with whatever is happening for me, I need to know what the next steps are. I need to know what's going to happen, when is it going to happen and how am I going to manage it. I mean even in my work life there's stuff, you know, there's always a sense for me of wanting to see things through to the end so I would want to know what's going to happen next so I can finish what I need to finish or when I'm going to finish or how I'm going to do it."*
What ii. Procedures (delivery, procedures and functionality)	Round the clock accessibility and availability (out of working hours)	- Chapter 1 findings Findings from literature within the thesis: - Nanton et al., 2018; Wootten et al., 2014	**Chapter 3 – participant 15:** - Participant 15 described feeling "*bombarded with leaflets" and* recalled the *"first port of call is the internet"* **Chapter 3 – Participant 5:** - Participants recalled the relief felt at diagnosis when the cancer was not as advanced as feared, describing how reading on the internet had helped to prepare resulting in feeling "*happy"* (P5) as it was not *"Stage 4"*. **Chapter 3 – Participant 2:** - P2 turned to the internet to find out more following a consultation and was "convinced" that the following appointment was not just routine, as on *"the notes it says 'suspected SCC' […] I took a copy of that, and obviously when I got home I googled 'SCC' to see what it was."*
	Distress thermometer or adapted tool to identify areas of concern	Findings from literature within the thesis: - Chambers et al., 2014	
	Confidentiality and anonymity for users	Findings from literature within the thesis: - Broom 2005; (Nanton et al., 2018; Wootten et al., 2014)	

	Signposting to support and reactive signalling	• Chapter 3 findings Findings from literature within the thesis: • Wootten et al., 2014; Zeliadt et al., 2013	
	Platform accessible across PC, tablet or mobile phone	• Chapter 1 findings Findings from literature within the thesis: • Armstrong et al., 2009; Brendryen & Kraft, 2008; Crankshaw et al., 2010; Dallery & Raiff, 2011; Kunutsor et al., 2010; Shet & de Costa, 2011; Strecher, Shiffman, & West, 2005; Titov, 2007; van Straten, Cuijpers, & Smits, 2008	
	Moderation support built in (users can flag issues to moderator)	Evidence from literature within the thesis: • Wootten et al. 2014	
	Safety net – moderator can identify participant safety issues	Evidence from literature within the thesis: • Wootten et al. 2014	
How (Modes of delivery)	Delivered through online portal	• Chapter 1 & 3 findings Evidence from literature within the thesis: • Ellis et al., 2015; Schmidt-Weitmann et al., 2015; Wootten et al., 2014	**Chapter 1:** • Wiljer et al.’s (2013) findings that those patients in the cancer early detection period report relying on the internet for most of their information. Nagler and colleagues (2010) found that clarification is characterized by both a greater range of source use, as well as a cross-source interaction that involves use of the internet. **Chapter 3 – participant 15:** • Participant 15 described feeling “*bombarded with leaflets” and* recalled the *“first port of call is the internet”*

Where Location and infrastructure	Person-centred approach	• Chapter 3 (page 74) and 4 findings Evidence from literature within the thesis: • Not a one-size-fits-all approach (Galdas, 2014; Wootten et al., 2014) • Individual has control of content (Wootten et al., 2014)	**Chapter 3 - participant 2:** • Recognition was given to the personal preferences for coping "*how I coped with it is not appropriate to everyone else. It was my unique set of circumstances"* (P2).
	Individual modules to enable individuals to 'pick and mix' to select most appropriate	• Chapter 3 and 4 findings Evidence from literature within the thesis: • Not a one-size-fits-all approach (Galdas et al., 2014; Wootten et al., 2014)	**Chapter 3 Participants 2, 4 & 13:** • Participants valued flexibility as each individual is "*different" (P2)* and *"reacts to […] diagnosis differently"* (P4). Recognition was given to an optimal individual approach being "*treated as a person not just a case"* (P13).

Development of ‘Men in Limbo’ using the PRISMS Taxonomy of Self-Management Support

The evidence from the empirical studies, and wider literature in the chapters, was used to to derive the development of the ‘Men in Limbo’ components, and subsequent modules. A staged developmental approach was taken using the Practical Systematic Review of Self-Management Support for long-term conditions (PRISMS) taxonomy of self-management support (Pearce et al., 2015). The taxonomy is a 14-item classification system of the components of self-management support interventions, is derived from over 100 systematic reviews of self-management support (Pearce et al., 2015). The taxonomy includes four dimensions including: the mode of delivery; the facilitator(s) delivering the support; the target of the intervention, and; the intensity, frequency and duration of the intervention (Pearce et al., 2015). The taxonomy explicitly details the description, including the ‘dose’ of the components and the ‘intensity’ of each specific component (as this may impact the effectiveness of the intervention). The taxonomy provides a common language of SMS for researchers, professional and commissioners and is a valuable tool to facilitate the conceptualisations of SMS to aid the reporting of interventions (Pearce et al., 2015). The classification tool, is intended as a comprehensive list of components that should be considered for inclusion in an intervention, to further define the proposed intervention content. A stepped approach was used to support the development of the intervention. The first stage was to map findings from the empirical studies, and theory, from the cancer early detection period research conducted (as illustrated in Table 18). The second stage was to apply the findings and the components of the self-management support intervention 14-item taxonomy. Each stage was made up of several tasks, and each completed task was collated to inform the next step, mapping the design and implementation schedule of the proposed intervention. The detail of the mapping included two major stages to the approach:

Stage 1 - mapping of Men in Limbo

The identified needs and themes, derived from the empirical studies with men in Chapters 3, 4 and 5, were mapped systematically into categories, and then subsequently, the data was categorised into components. This involved the sequencing of a number of different tasks, including the initial task of reviewing the findings from each of the chapters, examining them in depth and making notes. Then each chapter was taken sequentially and the identified themes from that chapter were taken and mapped alongside the evidence, including the supportive quotes, from the empirical study (an example of a number of these are outlined in the TIDier Checklist - refer to Table 17). In a tabular format, columns and rows held the data, and a summary was developed (within the table). Once all the chapters had been reviewed, and all the themes were mapped, the next step was a discussion with the supervisory team to explore systematically each identified theme, individually and across the range. Through these discussions, each theme was allocated and categorised, with additional new categories being added when the identified theme did not fit into any of the existing categories (as and when agreed). The next stage of the process involved creating and merging categories, where there was considerable overlap, with the aim to compile a comprehensive list of components. The tabular format held the data and enabled the categories to be merged systematically, following further discussions with the supervisory team.

The next phase involved the mapping of additional components, derived from the literature identified in Chapters 1 and 2, onto the existing list of components (as illustrated in Table 18). An iterative process of discussions enabled the development and further merging of categories together as agreed. This process resulted in the creation of the first iteration of the content of the ‘Men in Limbo’ intervention.

Several steps were taken to ensure that the risk of bias during the mapping of the data was minimised during Stage 1. This included peer debriefing, whereby the supervisory team were involved at several stages of the mapping, including: independently examining the findings, and providing feedback at the initial – and final - stages of mapping the themes. Further accuracy and consistency checking was done throughout the process.

Table 18 – Summary of the key findings mapped to build the contents of 'Men in Limbo'

Ch	Findings from each chapter with rationale	Condensed needs and themes	Men in Limbo Module and session
1	Prevalence of **fluctuating distress** in men across cancer early diagnosis period studies associated with increases in: intrusive thoughts about cancer; avoidance and anxiety due to a fear of diagnosis; anxiety levels of high-risk men **Stress-related reactions and anxiety** have been found increasingly in patients during the cancer early diagnosis period Evidence for the development of **support management of thoughts, and emotions, and self-management exercises to aid coping** (including mindfulness and relaxation, goal setting) and positive psychology tools (including gratitude exercises and recognising strengths-based exercises).	Fluctuating distress: intrusive thoughts about cancer; avoidance and anxiety due to a fear of diagnosis; anxiety levels of high-risk men Stress-related reactions and anxiety Support management of thoughts, and emotions, and self-management exercises to aid coping (including mindfulness and relaxation, goal setting) and positive psychology tools (including gratitude exercises and recognising strengths-based exercises).	1.3 Managing uncertainty and anxiety – what works for you Trying something different - introduction to relaxation and breathing techniques) 2.2 Dealing with and managing thoughts 2.4 Gratitude and trying something different (introduce breathing techniques) 1.4, 2.5, 3.4, 4.4, 5.4 Taking action: Preparing and planning Building knowledge What do you do for fun? 4.2 Exploring the mind body connection 4.3 Useful tips for managing stress Signposting for additional support 5.2 Looking after you: sleep, activity and a balanced intake
2	Evidence in **support of providing information, education and support before diagnosis** to help men to prepare and manage expectations about the processes and procedures during the cancer early diagnosis period (and reduce the anxiety experienced). **Health education interventions** provided effective knowledge for those who go on to receive a diagnosis of cancer (and can engage, prepare and inform men to manage uncertainty). Positive outcomes for men through interventions focused on **supportive information; educational resources and a combination of counselling and education** during the period. Confirmed that **no evidence based online peer support, self-management, intervention currently exists** for men to access during the period highlighting a gap in current provision and an opportunity for an intervention to address the unmet needs.	Health education components (to engage, prepare and inform men to manage uncertainty) Supportive information; educational resources and a combination of counselling and education	4.2 Exploring the mind body connection 4.3 Useful tips for managing stress Signposting for additional support 5.2 Looking after you: sleep, activity and a balanced intake 5.3 Identifying credible information and signposting for additional support

3	Unmet needs related to support for: isolated men; **navigation to credible tailored information sources**; **connectivity with other men's experiences** (to bring a sense of meaning, shared information and encourage positive coping strategies), and; **emotion management** (particularly anxiety and uncertainty). Unmet need in relation to **assistance to navigate** to credible tailored resources of information, and knowledge, to support and prepare them. Evidence for the use of the **internet as a useful tool** to gain information and knowledge during the waiting period, as findings confirmed the internet was the *'first port of call'*.	Navigation to credible tailored information sources; Connectivity with other men's experiences Emotion management	3.3 Navigating the health system and building knowledge 4.3 Useful tips for managing stress Signposting for additional support 5.2 Looking after you: sleep, activity and a balanced intake 5.3 Identifying credible information and signposting for additional support
4	Prioritisation of need for: **1) planning and preparation** **2) effective communication** **3) social support** **4) information and knowledge** Evidence for the **impact and value of social connectivity**, as men suggested that being connected was related to better management of emotions and perceived ability to cope effectively. A supportive individual alleviated distress and peer support improved confidence and gave reassurance. The **unmet social needs related to support: for isolated** men (single, widowed, or separated with a lack of a social support network) **and connectivity with other men's experiences** (to bring a sense of meaning, shared information and encourage positive coping strategies). Unmet need was found to be related to being able to **understand and decipher credible sources** which presented a challenge. **Need for normality, acceptance and belonging** (to reduce feelings of social isolation) Evidence from men's accounts highlight the **coping mechanisms used (problem-focused and emotion-focused) supported the adaption to the threat of illness**, helping to alleviate the anxiety experienced. Benefits included feeling more in control, and more confident to cope, through planning and compartmentalising the process. The use of distraction gave men purpose and status which was valued, whereas humour and accruing information relieved anxiety and lightened the perceived burden.	Planning and preparation Effective communication Social support Information and knowledge Social connectivity Understand and decipher credible sources of information and support Normality, acceptance and belonging – to reduce feelings of social isolation Highlight coping mechanisms - problem-focused and emotion-focused to support adaption to the threat of illness	1.2 Communication with healthcare professionals – getting the best out of your consultation 2.2 Communication with family and friends – managing difficult conversations. 2.3 Building and using your support networks. Plotting your support (and identifying others) 3.3 Navigating the health system and building knowledge 4.2 Planning ahead 4.4 Useful tips for managing stress Signposting for additional support 5.3 Identifying credible information and signposting for additional support

5	Evidence of the **acceptability and therapeutic benefit of reflection** activated through giving voice to men’s interpretation and perceived meaning of their experiences. Insight into the experiences at a far deeper level than is possible through text alone and strengthens the argument for using **visual media to engage men** in groups for whom in person face-to-face health related information may be more challenging. Supports men to articulate experiences for other men’s benefit by **connecting with an experience**, rather than simply explaining it, giving greater impact. **Range of coping skills** used during the period to help men to cope effectively. The intervention needs to introduce and encourage users to try an array of positive coping strategies, as different strategies will be more useful at certain times. **Supports productivity** during the cancer early diagnosis period. The digital stories, embedded within the intervention, provide a readily accessible mechanism for other men to gain benefit from and **communicate the normalcy of emotions and thoughts.** Provides a **warning to other men about the potential pitfalls** while **supporting them by sharing experiential knowledge to promote well-being** for all. A sense of responsibility gave motivation to give back for other men’s benefit (even forsaking emotions such as embarrassment), and digital stories were valued for the opportunity to **understand and connect with an experience** rather than simply explaining it, giving greater impact. Participants were keen to **communicate supportive warnings** to other men whilst encouraging them to **find the best way through** the state of flux.	Opportunity for reflection Visual media to engage men Connecting with an experience To introduce and encourage an array of positive coping strategies Communicate the normalcy of emotions and thoughts Support through sharing experiential knowledge to promote well-being Encouragement to find the best way through.	3.2 Building control and identifying strengths 4.3 Useful tips for managing stress Signposting for additional support 5.2 Looking after you: sleep, activity and a balanced intake

Stage 2 – refining Men in Limbo

The content derived in Stage 1 were than mapped against components described in the PRISMS taxonomy of self-management support (Pearce et al., 2015). The components of the PRISMS taxonomy were mapped and incorporated into, the data for the Men in Limbo modules, which was modified as necessary. This step was conducted by the researcher in collaboration with the supervisory team. Throughout this iterative process, components described in the included studies that did not fit comfortably into the components were identified and discussed for resolution. This allowed for elements to be challenged and, if necessary, altered to incorporate new components. The two-staged approach resulted in five modules being produced.

Evidence suggests having regular timely support to deliberate on the advantages and disadantages of certain behaviour can make it more likely that motivation, or activation to change develops (Hibbard & Gilburt, 2014; Janis, 1959; Prochaska & DiClemente, 1982). It is recognised that tailored support can enable individuals to receive appropriate assistance at the necessary time for them, which can increase the impact of the support (Noar, Benac & Harris, 2007). The rationale for 5 modules was developed through reflection on the existing evidence. For example, a systematic review of self-management courses has suggested that short courses (less than 8 weeks) may be more effective than longer ones (more than 8 weeks) with a general average of 6 weeks per course (Carnes et al., 2012). Supportive evidence from other studies suggests that both long and short-term programmes are effective (Hauser et al., 2009; Guzman et al., 2002; Walsh et al., 2006). However, it has been argued that shorter courses may provide better retention of participants and, therefore, provide more opportunities to motivate and support participants (Carnes et al., 2012). Self-management interventions, within mental health, have demonstrated the effectiveness of brief interventions which are acceptable to participants and often preferred (Watt et al., 2006; Brown et al., 2004; Wiseman et al., 2002). Effectiveness, and beneficial outcomes, have been shown even after a brief one 3-hour intervention (Watt et al., 2006). However, in conclusion having regular tailored support - and time to deliberate - in between modules, is recognised as the important factor (rather than the specific number of modules) as it may make it more likely that motivation or activation to change may occur. The cancer early detection period, from testing to confirmation of test results, generally takes several weeks as Participant 14 in Chapter 3 illustrated:

> *"there were times when it was just a week between each step but then it got to being several weeks between each step, and that's when it became more worrysome. I mean you just want it to be sorted really, but they can't, they won't sort it until they've got the full results themselves and they've had chance to go through those results and decide whats best for you as a patient."* (P14)

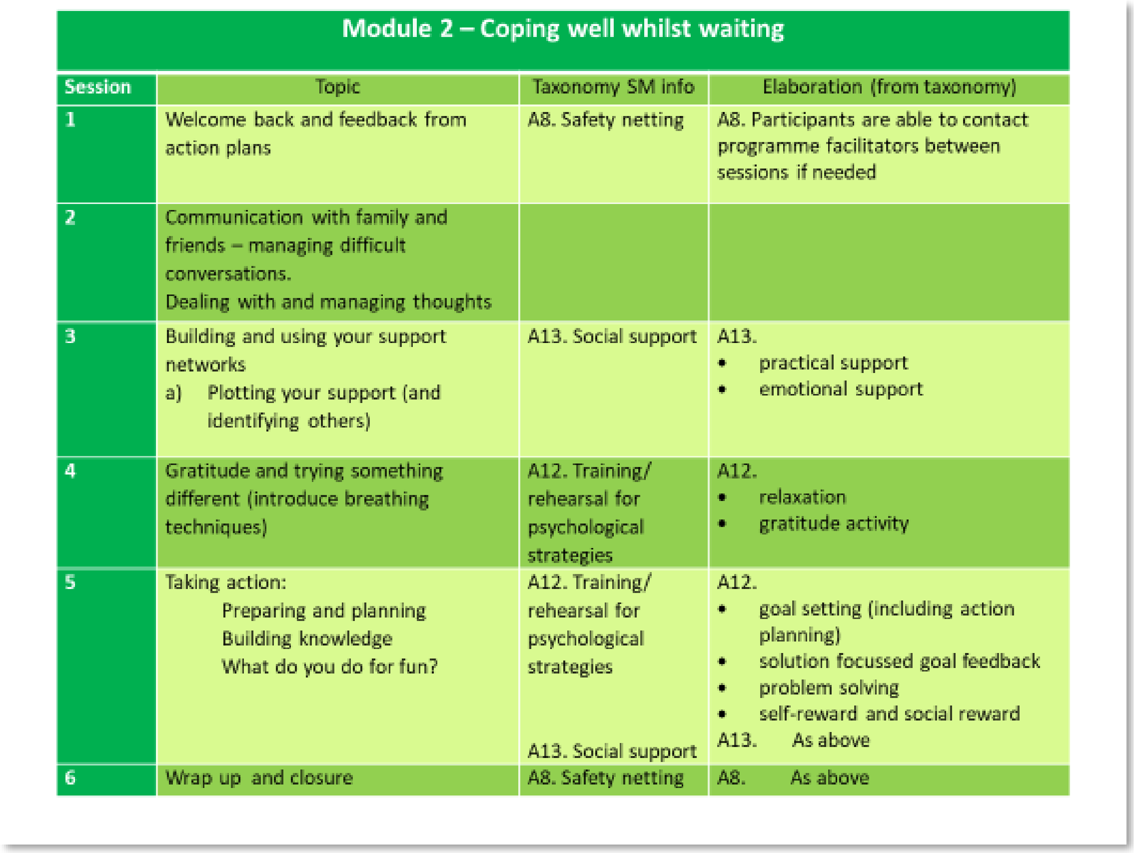
Therefore, although there is a recommendation that modules are accessed weekly - over 5 weeks - the recommendation is purposely flexible, to allow for the needs of each individual man to be incorporated. The five modules are outlined in Figure 12:

Over-arching dimensions:

- Mode of delivery – web based
- Personnel delivering the support – self-directed with lay/professional moderation
- Targeting - individual men during the cancer early detection period
- Intensity, frequency and duration of the intervention – 5 modules recommended weekly (can be flexible to meet the needs of the individual man in ‘pick and mix approach)

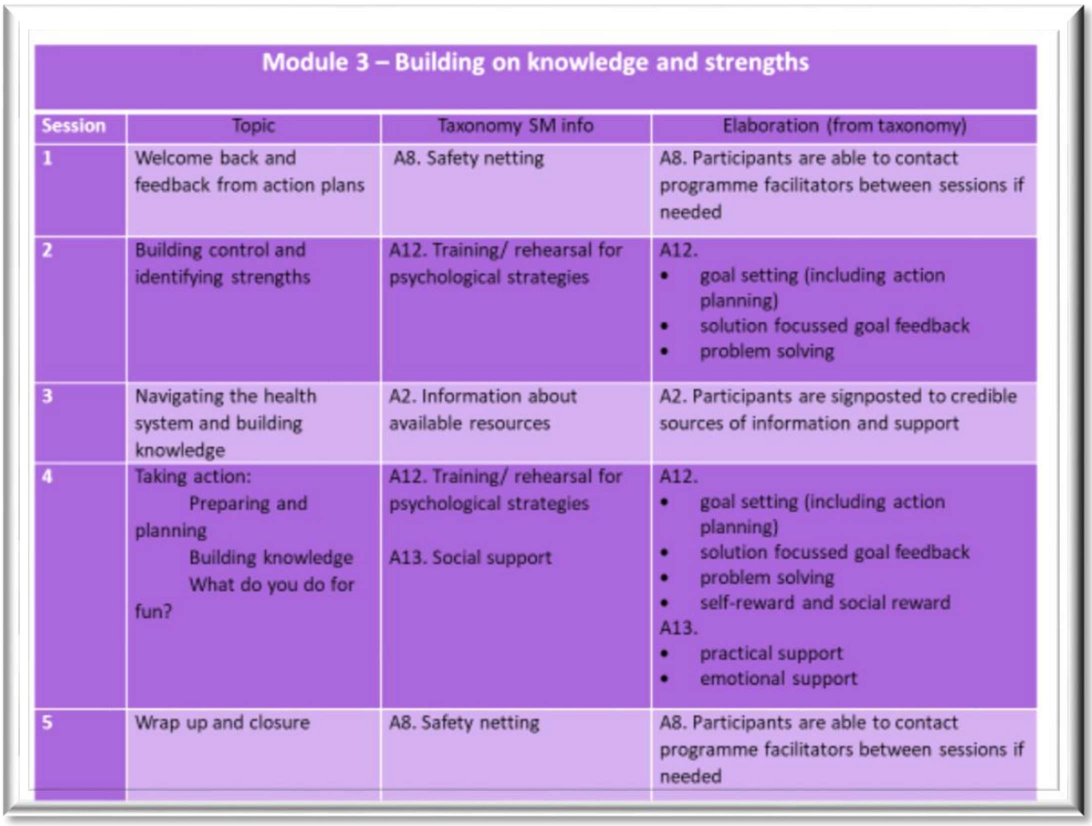
Figure 12 – Men in Limbo modules

Module 1 – Having better conversations			
Session	Topic	Taxonomy SM info	Elaboration (from taxonomy)
1	Introduction – experts by experience building on what you know already!	A8. Safety netting	A8. Participants are able to contact programme facilitators between sessions if needed
2	Communication with healthcare professionals – getting the best out of your consultation	A9. Training/rehearsal to communicate with health care professionals	
3	Managing uncertainty and anxiety – what works for you? - Trying something different - introduction to relaxation and breathing techniques?)	A12. Training/rehearsal for psychological strategies	A12: • relaxation • problem solving • gratitude activity • managing stress
4	Taking action: Preparing and planning, Building knowledge. Sharing -what do you do for fun?	A12. Training/ rehearsal for psychological strategies A13. Social support	A12. • goal setting (including action planning) • solution focussed goal feedback • problem solving • self-reward and social reward A13. • practical support • emotional support
5	Wrap up and closure	A8 Safety netting	As above



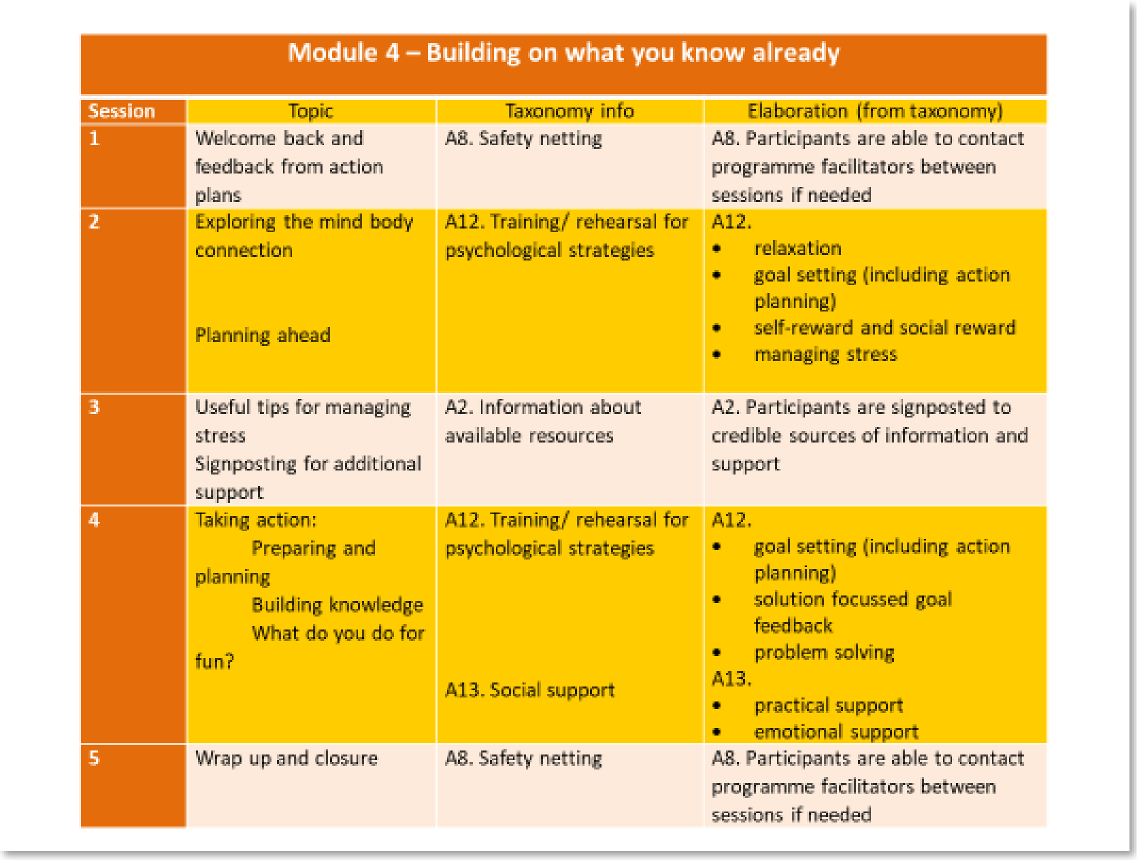
Module 2 – Coping well whilst waiting

Session	Topic	Taxonomy SM info	Elaboration (from taxonomy)
1	Welcome back and feedback from action plans	A8. Safety netting	A8. Participants are able to contact programme facilitators between sessions if needed
2	Communication with family and friends – managing difficult conversations. Dealing with and managing thoughts		
3	Building and using your support networks a) Plotting your support (and identifying others)	A13. Social support	A13. • practical support • emotional support
4	Gratitude and trying something different (introduce breathing techniques)	A12. Training/ rehearsal for psychological strategies	A12. • relaxation • gratitude activity
5	Taking action: Preparing and planning Building knowledge What do you do for fun?	A12. Training/ rehearsal for psychological strategies A13. Social support	A12. • goal setting (including action planning) • solution focussed goal feedback • problem solving • self-reward and social reward A13. As above
6	Wrap up and closure	A8. Safety netting	A8. As above



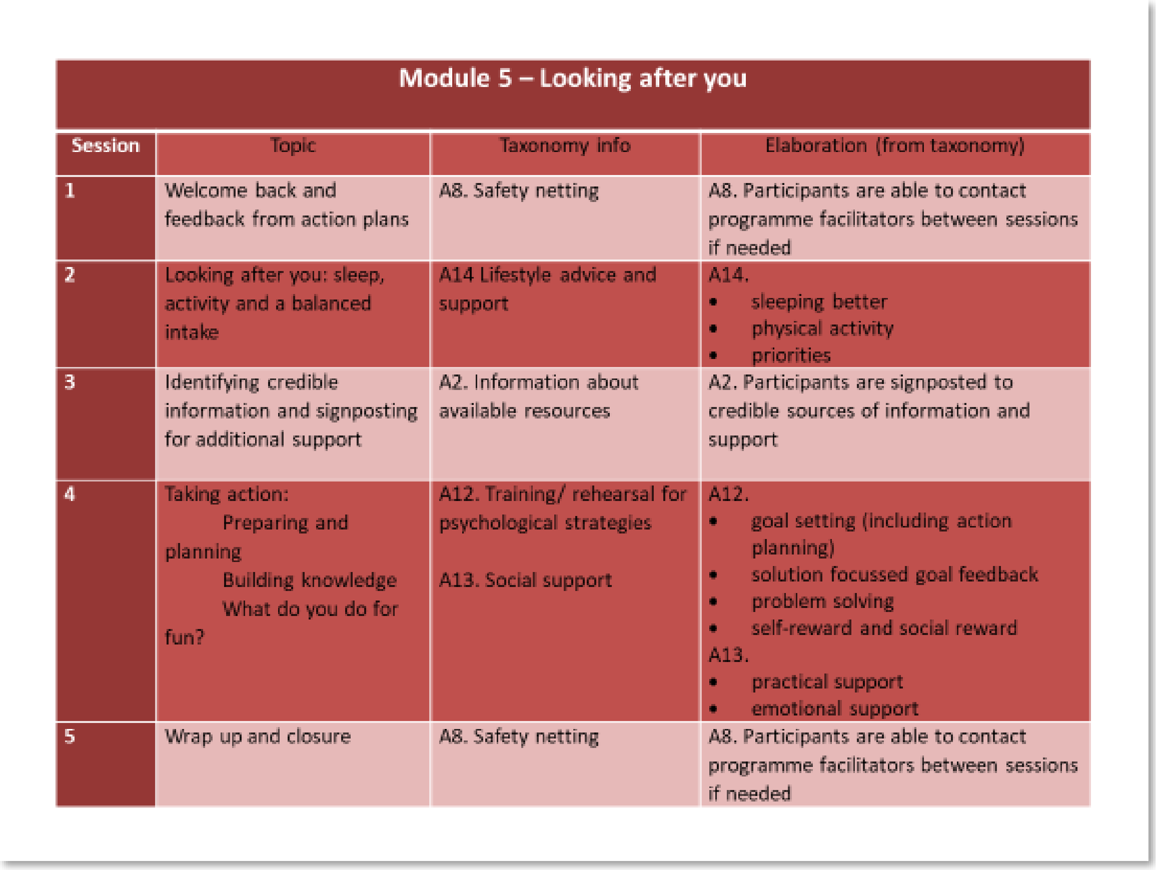
Module 3 – Building on knowledge and strengths

Session	Topic	Taxonomy SM info	Elaboration (from taxonomy)
1	Welcome back and feedback from action plans	A8. Safety netting	A8. Participants are able to contact programme facilitators between sessions if needed
2	Building control and identifying strengths	A12. Training/ rehearsal for psychological strategies	A12. • goal setting (including action planning) • solution focussed goal feedback • problem solving
3	Navigating the health system and building knowledge	A2. Information about available resources	A2. Participants are signposted to credible sources of information and support
4	Taking action: Preparing and planning Building knowledge What do you do for fun?	A12. Training/ rehearsal for psychological strategies A13. Social support	A12. • goal setting (including action planning) • solution focussed goal feedback • problem solving • self-reward and social reward A13. • practical support • emotional support
5	Wrap up and closure	A8. Safety netting	A8. Participants are able to contact programme facilitators between sessions if needed



Module 4 – Building on what you know already

Session	Topic	Taxonomy info	Elaboration (from taxonomy)
1	Welcome back and feedback from action plans	A8. Safety netting	A8. Participants are able to contact programme facilitators between sessions if needed
2	Exploring the mind body connection Planning ahead	A12. Training/ rehearsal for psychological strategies	A12. • relaxation • goal setting (including action planning) • self-reward and social reward • managing stress
3	Useful tips for managing stress Signposting for additional support	A2. Information about available resources	A2. Participants are signposted to credible sources of information and support
4	Taking action: Preparing and planning Building knowledge What do you do for fun?	A12. Training/ rehearsal for psychological strategies A13. Social support	A12. • goal setting (including action planning) • solution focussed goal feedback • problem solving A13. • practical support • emotional support
5	Wrap up and closure	A8. Safety netting	A8. Participants are able to contact programme facilitators between sessions if needed



Module 5 – Looking after you

Session	Topic	Taxonomy info	Elaboration (from taxonomy)
1	Welcome back and feedback from action plans	A8. Safety netting	A8. Participants are able to contact programme facilitators between sessions if needed
2	Looking after you: sleep, activity and a balanced intake	A14 Lifestyle advice and support	A14. • sleeping better • physical activity • priorities
3	Identifying credible information and signposting for additional support	A2. Information about available resources	A2. Participants are signposted to credible sources of information and support
4	Taking action: Preparing and planning Building knowledge What do you do for fun?	A12. Training/ rehearsal for psychological strategies A13. Social support	A12. • goal setting (including action planning) • solution focussed goal feedback • problem solving • self-reward and social reward A13. • practical support • emotional support
5	Wrap up and closure	A8. Safety netting	A8. Participants are able to contact programme facilitators between sessions if needed

Tailoring the intervention to appeal to men

Recent studies have shown that the acceptability of self-management support interventions targeting men can be enhanced when the context, content, and delivery style is bespoke to the valued aspects of male identities (Galdas et al., 2014; Hunt et al., 2013; Hunt et al., 2014a; Hunt et al., 2014b; Robertson et al., 2014). In line with findings from the empirical studies, it is acknowledged that the intervention needs to be conceptually appealing to men and its content tailored and relevant to their needs, otherwise it will be perceived as incompatible. Therefore, based on the lived experiences of men who have been through the cancer early detection period, it is suggested that the content of this intervention has authenticity, and is grounded in theory and evidence-based practices. It presents a bespoke approach that has the flexibility to address the issues identified as important to men during the period. However, it is equally important that the intervention engages with men visually, by using images that are meaningful to men. Visual appeal and meaningful engagement is imperative for several reasons. Evidence indicates that visual materials that include images of real men, and normalise participation, make the intervention more acceptable and more likely to succeed (Anderson et al., 2016). As outlined earlier in the thesis, the use of images to elicit changes in behaviour and mechanise change, offers considerable power to influence behaviour through emotion and cognition (Bradley & Lang, 1999; Ito, Cacioppo, & Lang, 1998). Previous research has found visual media to be more memorable (Gardner & Houston, 1986; Paivio, Walsh, & Bons, 1994; Prabu, 1998), to have a longer-term impact (Cameron, 2003), and to be less dependent on the literacy levels or language skills of the viewer (DeWalt et al., 2004). Chapter 5 discussed how using visual media to communicate messages with others, termed ‘visual literacy’ (Ausburn & Ausburn, 1978; Avgerinou & Ericson, 1997), extends the reach to wider groups of the population. Therefore, ensuring that the intervention uses visual media to engage with its audience offers opportunities to reach men in groups for whom face-to-face health-related information may be more challenging.

In consideration of the need to be visually appealing to men, it is crucial that the intervention uses images of real men (not models) from a wide variety of demographics (age, ethnicity etc.) to ensure men can associate themselves with it. The desire to see ‘men like them’ represented replicates findings from several other recent studies (Bunn et al., 2016; Hunt et al., 2014a; Hunt et al., 2014b). This was also considered during the development of the peer digital stories (as outlined in Chapter 5), which included a variety of men of different ethnicity and ages. An illustration of the front welcome screen is included in Figure 13.

Figure 13 – Screenshot of welcome page

Welcome to
Men in Limbo
Designed with men for men

Log in/ register here:

An additional consideration is the most appropriate and appealing layout (and language) of the intervention to ensure optimal engagement with users. Studies have found that using an action-orientated approach and perceived masculine terminology ('active' positive language, such as 'building on'), with humour, can be attractive to men (Ellis et al., 2015). Men prefer self-help (Ellis et al., 2013; Farrand et al., 2006) which supports the need to be in control. In acknowledgement of these preferences, the layout of the intervention needs to allow the individual to choose components of the intervention which meets their needs, enabling them to 'pick and mix' from the topics. Proactive moderation (where users can block unwanted content) and reactive moderation (users can report inappropriate content to a system moderator) would be embedded into each module and users could block or flag to the moderator as appropriate. By allowing individuals to personalise their use and manage their own experience of the intervention, users gain a perceived sense of ownership.

Next steps - prototyping

Based on the evidence outlined and the structure, components and functions of the intervention – defined in the TIDieR checklist (Table 17) and the PRISMS taxonomy of Self-

Management Support (SMS) - the next step in the development of this research is to build a fully functioning online prototype, for the purposes of conducting usability testing and subsequently feasibility testing to understand the wider issues from a future user's perspective. In line with the MRC framework for developing complex interventions, a series of studies may be needed to decipher the most appropriate design of a full-scale evaluation (Craig et al., 2008). It is proposed that a study using 'think aloud' methodology would be an advantageous next step in the development of the intervention (Ericsson & Simon, 1993; Van Someren, Barnard, & Sandberg, 1994). The methodology enables a powerful approach to assess the information needs and reasoning of the user, whilst sourcing any practical issues with the interface. Feeding the problems back into the extended usability design period ensures a proactive solution to decreasing problems further down the line of feasibility testing. Previous studies have identified that employing the approach has caused a ten-fold decrease in user issues and problems during further follow-up study (Kushniruk & Patel, 1998; Kushniruk et al., 1996). There are many areas of interest for future studies assessing the usability and feasibility of the intervention. Initially, during the usability phase, it is imperative to address the following usability factors (Nielsen, 1993):

- Learnability – is the system easy for users to learn quickly to get going with it?
- Efficiency of use – are users able to perform tasks productively?
- Memorability – is it easy for users to remember how to use the system when they come back to it?
- Error recovery – do users make minimal errors and can they recover quickly from any they make?
- Subjective satisfaction – are users satisfied with the system and using it?

In addition, a further feasibility study would explore whether the intervention would work for the intended cohort of users. Within this, there is also the potential to identify the wider facilitators to engaging men with the intervention, including its advertising and marketing. This highlights important considerations for future implementation. It is imperative that certain groups of men (such as those needing support) recognise the value of the intervention and the opportunity it presents for them to gain support during their appraisal of the cancer early detection period.

In line with the MRC framework, consideration needs to be given to the careful design of the next stages. This ensures processes and procedures are managed effectively to optimise the required recruitment and retention of users to evidence robust testing (Craig et al., 2008). It is acknowledged that the next steps to the development of the intervention are to create a fully functioning user-led co-designed prototype to allow for a usability study to be done. The examples below give an indication of the proposed layout to support a flexible, person-centred, approach to the way the intervention is used (see Figure 14). An illustrated prototype of Module 1 is included in Figure 15.

Figure 14 – Example of prototype – potential organisational layout of the intervention

Figure 15 - Screenshot of example prototype - Module 1

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Summary of intervention

This chapter has outlined the proposed intervention for men during the cancer early detection period. The empirical studies carried out through this research have added new findings and evidence to the field of psychosocial support during the cancer early detection period. The proposed intervention has been developed in line with the notion that interventions targeting men specifically need to align with the valued aspects of men's identities (Hunt et al., 2013; Hunt et al., 2014a; Hunt et al., 2014b; Robertson et al., 2014).

The purpose of the intervention has been made explicitly clear by outlining the structure using the defined TIDieR checklist (and guide) (Hoffmann et al., 2014) and the PRISMS taxonomy of SM Support (Pearce et al., 2015). Careful consideration has been given to the space created within the intervention for discussion and exploration of issues to ensure men can trust and feel supported within it. The valuable lived experiences of peers, delivered via digital stories, brings a sense of belonging and normality (Cramer et al., 2014;

Dickerson et al., 2011; Gooden & Winefield, 2007; Oliffe et al., 2010; Sullivan, 2003). The components and activities are encapsulated by a positive psychology and Cognitive Behavioural Therapy (CBT) approach which build on the strengths that men bring with them, and acknowledgement is given to their expertise. By recognising and building on skills, taking a strengths-based approach, the aim is to increase men's self-efficacy to self-manage during the cancer early detection period and value the skills they have to cope effectively.

Being able to support those who need it most is imperative. Therefore, in terms of the effectiveness of the intervention, future studies have the opportunity to measure baseline scores of distress and wellbeing which may help to determine for whom the intervention is most effective in terms of outcome measures. There is scope for the intervention to be evaluated with certain groups of men (higher risk and needing support) to gain the most impact and understand who it works for and under what circumstances. This would allow for additional studies in the field of patient stratification, ensuring it is targeted at those men who need it most.

Strengths and limitations

There is little known about the effectiveness of self-management support for men during the cancer early detection period. The systematic, needs-led, mapping approach taken is a major strength of this research because the identified needs of men have informed the choice of components included within the intervention. By adopting this approach, and the mapping of wider literature, it is proposed that the rigorous process taken to developing 'Men in Limbo' – grounded in men's lived experience of the period – makes it more likely to be useful and acceptable to future users. The needs and perspective of the intended users are a vital part of ensuring that interventions are usable and engaging (Baker, Gustafson, & Shah, 2014; Pagliari, 2007; van Gemert-Pijnen et al., 2011). Research in intervention development confirms that when users are involved in the development, there is a 'higher chance of producing implementable data' (Craig et al., 2008). Therefore, a major strength of the intervention is that it has an increased chance of being more acceptable to users because it is based on the identified needs of men during the cancer early detection period.

Another strength of the research is that by using both the TIDieR checklist, and the PRISMS taxonomy of SMS, a robust synthesis of evidence has clearly described and detailed the intervention sufficiently. Thus, the transparent process will enable the intervention to be comprehensively replicated or built on by other researchers in the future. The process has produced high quality reporting by using these evidence-based tools to describe and outline the content, process and outcomes associated with ‘Men in Limbo’. The proposed intervention is the first developed through this approach, addressing the need for supportive care for men during the cancer early detection period.

Due to the paucity of research in the cancer early detection period, specifically on men, the focus of this research was to gather evidence from men to understand their lived experiences of the period. The focus was not on engagement with the healthcare professionals that support men during the stage. However, the lack of healthcare professional input into the development of the intervention may be viewed as a limitation. This could be mitigated by further opportunities to engage with healthcare professionals, through the feasibility testing and next stages of development and evaluation, to incorporate their involvement for the benefit of their patients.

Conclusion

In conclusion, the cancer early detection period offers an opportunity to intervene and engage with men in distress to support them to cope and manage effectively. It presents an optimal time to raise awareness of information, support and evidence-based coping strategies available to them. The proposed intervention illustrated within this chapter presents future men with an opportunity to recognise their own strengths and skills. In so doing, it is proposed that future users who appraise the period as distressing can be provided with the space to reflect upon the potential threat, positively reappraise, and effectively cope and manage during the period of the uncertainty. The proposed intervention provides an original contribution to knowledge within the field of cancer early detection and it, alongside wider research, paves the way for future studies investigating the psychosocial support needs of men during the cancer early detection period.

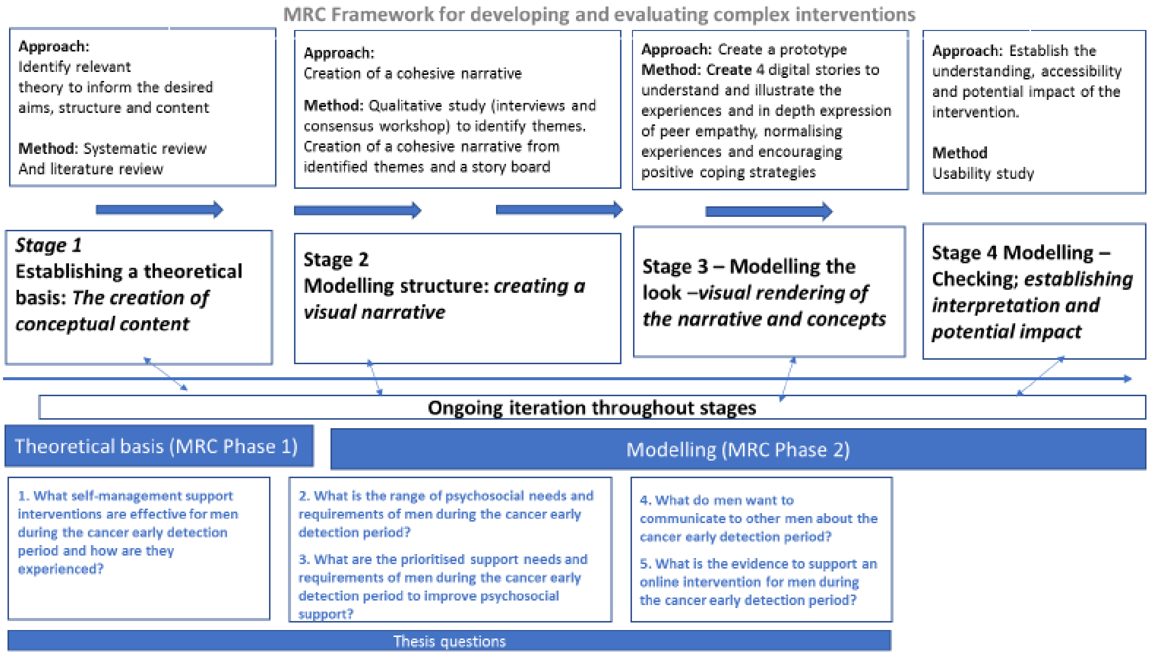
Chapter 7 – Summary and Conclusions

Introduction

Chapter 6 provided an overview of how the original research outlined in this thesis contributes to the limited knowledge focused on men, during the cancer early detection period, and presented findings in relation to the research questions posed. The chapter concluded by outlining a proposed online self-management intervention, detailing how the findings contributed to its development, content and structure. In line with the MRC Framework for evaluating and reporting complex interventions (refer to Figure 16). (Craig et al., 2008), the exploratory nature of the empirical studies, and their findings, provide some early phase research that could be used to inform the next phase of intervention.

The aim of this final chapter is to integrate the findings and put forward a collated synopsis of how this research makes some contribution to the limited knowledge focused on men during the cancer early detection period, and presents findings in relation to the research questions posed. The limitations of the findings are outlined, and a section on personal reflexivity is detailed. Finally, in response to the findings, this chapter presents some implications for future healthcare policy, practice and further research.

Figure 16 - MRC Framework for developing and evaluating complex interventions



Summary of key research findings

Chapter 1 presented a comprehensive narrative review of the wider literature in relation to the broader context of the cancer early detection period and the experiences of men with cancer. It set out the broader causes, consequences and prevalence of psychosocial issues for men, and highlighted the limited understanding of the psychosocial processes linked with the experiences of men during the cancer early detection period. This provided the rationale for the exploratory work needed, and led to the identified questions for the thesis, as outlined below:

1. What self-management support interventions are effective for men during the cancer early detection period, and how are they experienced?

2. What is the range of psychosocial needs and requirements of men during the cancer early detection period?

3. What are the prioritised support needs and requirements of men during the cancer early detection period to improve psychosocial issues?

4. What do men want to communicate to other men about the cancer early detection period?

5. What is the evidence to support the content of an online intervention for men during the cancer early detection period?

Chapter 2 set out to explore the effectiveness of current interventions to support men, examining the outcomes associated with the interventions through conducting a mixed methods systematic review of the literature, thus addressing research question 1. In summary, the findings borne out of the review identified:

- Interventions introduced during the cancer early detection period do not appear to cause anxiety, and can prepare men, and reduce anxiety, for diagnosis.
- Some early cancer detection period interventions for men, with positive outcomes, focus on supportive information (both educational resources and a combination of counselling and education).

- Health education interventions can provide effective knowledge for those who go on to receive a diagnosis of cancer, and can engage, prepare and inform men to manage uncertainty.
- No evidence-based online self-management support intervention currently exists for men during the cancer early detection period.
- More empirical research is needed to be able to identify and prioritise the needs of men, and their subjective experiences, during the period of uncertainty.

The systematic review revealed a limited number of studies exploring self-management support interventions with men during the cancer early detection period, which made it difficult to make definitive conclusions on effectiveness and experiences. However, it tentatively suggested that some interventions introduced during the cancer early detection period appear to not cause anxiety (and can prepare men, and reduce anxiety, for diagnosis). The findings reinforce previous research highlighting the lack of evidence on intervention effectiveness during the early cancer detection period (Wiljer et al., 2012, 2013) and add to wider evidence that suggests resources, support and information provision can positively impact on health and wellbeing outcomes in men (Krumwiede & Krumwiede, 2012). The review, although limited, concluded that no evidence-based online self-management support intervention currently exists, and highlighted the need for further empirical research to understand and identify men's range of needs across numerous cancer tumour sites. Thus, the need for further empirical research was identified, to understand and identify the full range of men's experiences during the cancer early detection period.

The findings from the first empirical study (outlined in Chapter 3) build on the identified need to establish the range of experiences of men who had personal experience of the cancer early detection period. Through a qualitative retrospective study of in-depth semi-structured interviews, the study addressed question 2. In summary, the findings suggested:

- Unmet needs related to support for: isolated men (single, widowed, or separated with a lack of a social support network); navigation to credible tailored information sources (and knowledge, to support and prepare them); connectivity with other men's experiences (to bring a sense of meaning, shared information and encourage positive coping strategies), and; emotion management (particularly anxiety and uncertainty).

- The expectations of ‘being a man’ appeared to impact on men’s perceived experiences of the period, and it is suggested that effective communications with healthcare professionals can make a positive difference to their perceptions (of the period) and subjective wellbeing.
- There is some evidence supporting the use of the internet as a beneficial tool to gain information and knowledge during the waiting period, as some of the findings confirmed the internet was the *‘first port of call’*.

These tentative findings, which highlight social connection and information needs within the cancer early detection period, add to the limited body of literature, extending existing knowledge beyond prostate-specific research, into different tumour sites and diagnostic outcomes (Boehmer & Babayan, 2005; Ervik, Nordoy, & Asplund, 2010; Majumder et al., 2014; Matsunaga & Gotay, 2004; O’Shaughnessy et al., 2013a; Rivers et al., 2012; Walsh & Hegarty, 2010). It could be suggested that the findings add some weight to the opportunity that exists to use online resources for future men to gain information and knowledge during the cancer early detection period. Thus, highlighting the opportunity that the online environment presents in supporting men’s emotional needs without compromising their masculine norms (such as stoicism) (Galdas & Baker, 2015; Robertson, 2007; Pollard, 2007). These main findings of the study suggest that there are a range of factors that influence both the individuality of experiences and the commonalities of need that each man encounters. Nevertheless, although the range of needs and experiences vary from individual to individual, a set of core valued needs (common to the majority) exists. The core valued needs included: navigation to credible tailored information sources; connectivity with other men’s experiences, and; emotion management, and the study highlighted the opportunity to focus on those needs.

In response to the identified gap and opportunity to gain consensus of the priority of needs to support men with psychosocial needs, a qualitative study involving 8 men addressed question 3. The study identified:

- The greatest prioritised needs related to: the ability to plan; have effective communications with healthcare professionals; gain social support and accrue information and knowledge.
- Men value the ability to plan and prepare, giving a sense of control as they navigate the uncertainty of the period

- Value is gained from the opportunity to interact with professionals, ask questions, and gain clarity, which is suggested to help support the anxiety experienced
- A number of men had a need for normality, acceptance and belonging, to reduce feelings of social isolation. It was suggested that a supportive individual alleviated distress, and peer support improved confidence and gave reassurance. Having a supportive individual and learning from peers' experiences was suggested to provide emotional support to cope and manage thoughts, feelings and uncertainty.
- Gaining information and knowledge supported decision making. An identified unmet need was related to the ability to understand and decipher credible sources.

These tentative findings concur with the body of literature consistent with the action-orientated, clear purpose approach that has been found to be appealing to men, in line with a preference for problem-focused coping (Adamsen, Rasmussen, & Pedersen, 2001; Barlow, Edwards, & Turner, 2009a; Barlow, Turner, & Gilchrist, 2009b; Bell et al., 2010; Bourke et al., 2012; Dickerson et al., 2011; Gray et al., 1996; Oliffe et al., 2010; Seale, 2006; Sullivan, 2003; Seymore-Smith, 2008). Nevertheless, the study highlighted the value placed on emotion-focused coping, revealing the need for normality, acceptance and belonging (to reduce feelings of isolation). It suggested that access to a supportive individual alleviated distress, and peer support improved confidence and gave reassurance. This provides some challenge to other findings in the area of gender difference of cancer patients' needs, which suggests that generally women are more inclined to look for emotional support, whereas men are more inclined to seek ways to enhance their knowledge (Dale et al., 2004; Klemm et al., 1999; Sharf, 1997). The findings suggested that value was placed on gaining insight, knowledge and connection with other men's experiences. However, many barriers - including the brevity of the cancer early detection period - presented significant challenges to accessing other men with experiential knowledge. In accordance with the wider aim of the thesis, the study identified the need to find a way to support and enable men to access other men's experiences and to gain peer support during the brief period.

The arts-based participatory method, a digital story approach, was used to collect data from 4 men in order to gain access to their experiences of the early cancer detection period. The study, outlined in Chapter 5, addressed question 4 and revealed:

- A desire to warn other men about the potential thoughts and feelings, during the period, to help to prepare them in a supportive way. Warnings were based on individuals' experiences, encouraging others to reach out for social support and encouragement to ask for help.

- Digital stories can provide a readily accessible mechanism for other men to benefit from and communicate the normalcy of emotions and thoughts. They provide the opportunity to warn other men about the potential pitfalls whilst promoting well-being through the sharing of experiential knowledge.
- A sense of responsibility can motivate participants to 'give back' for other men's benefit during the period.
- Arts-based co-design participatory methods are suggested as acceptable and valuable to men during the cancer early detection period and can lead to the articulation, and transformation, of experiences.
- It is suggested that digital stories are one valuable method to understand and connect with men's experiences, giving greater impact to the audience, and providing therapeutic benefit through reflection for the storyteller.
- Visual media methods can enable insight to be gained into experiences at a far deeper level than is possible through text alone, and can provide an opportunity to engage men, in groups, for whom in-person face-to-face health related information may be more challenging.
- A range of coping skills is used by men during the cancer early detection period to cope effectively. Visual media methods can provide an opportunity to introduce and encourage other men to try out other positive coping strategies.

Through reflection, 'supportive warnings' were used to warn other men about the potential pitfalls while supporting them by sharing experiential knowledge to promote well-being for all (Broom, 2005; Sillence & Mo, 2014). This finding adds weight to the findings of other studies, such as those in the field of cancer genetics, with individuals facing the prospect of cancer who wanted the opportunity to listen to other individuals' similar experiences to gain a better understanding of the processes involved and help to manage expectations (Iredale, Gray, & Murtagh, 2002; Phelps et al., 2007). Therefore, it could be argued that providing digital stories from men who have experienced the cancer early detection period, talking about the strategies they used to cope and providing information in an accessible and engaging format, has the potential to help prepare individuals to cope during the period (Iredale, Gray, & Murtagh, 2002; Metcalfe et al., 2009; Phelps et al., 2007). Thus, it could be argued that the stories have the potential to act as resources to help individuals form and illustrate their identity, giving others a sense of who they are: this finding is in keeping with previous wider research (Schiffrin, 1996; Wortham, 2000).

By framing support as ‘helping others’ or illustrating a clear link to facilitating ‘productivity’, men may be more willing to accept help themselves. This link corroborates with wider studies outlining how giving back is important for male identity and self-esteem (Cramer et al., 2014; Galdas et al., 2014; Gray et al., 1996; Oliffe et al., 2008; Seymore-Smith, 2008).

The tentative findings suggest that a process of co-designing and creating digital stories can be an acceptable mechanism for some men to highlight the psychosocial impact of cancer. In summary, it could be suggested that this study adds to the case for change in dispelling the assumption that some men do not participate in creative activities (Geue et al., 2010; Hammond et al., 2018), and contributes to the field exploring men’s experiences of engaging with arts-based approaches within the field of cancer (Saunders, Hammond, & Thomas, 2018). However, the substantial investment of resources (training, audio-visual and IT equipment) may limit and prohibit widespread use.

The last chapter (6) presented how the collated empirical findings and evidence informed the development and design of the ‘Men in Limbo’ intervention, to address question (5). The study outlined and suggested that:

- New and important evidence has led to the development of the ‘Men in Limbo’ intervention built from the concept of a strength-based approach, encouraging the self-management of distress, and effective coping, during the cancer early detection period.
- The ‘Men in Limbo’ intervention presents an original contribution for future development and research during the cancer early detection period. It provides a suggested framework for future researchers and intervention developers.

The main collated findings provided tentative evidence to support the design, development and specifically the content of the ‘Men in Limbo’ intervention. As it is suggested that no current online intervention exists, it could be argued that this intervention research adds some new findings and evidence to the field of psychosocial support during the cancer early detection period, aligned with valued aspects of men’s identities (Hunt et al., 2013; Hunt et al., 2014a; Hunt et al., 2014b; Robertson et al., 2014).

The purpose of the intervention was made explicitly clear by outlining the structure using the defined TIDieR checklist (and guide) (Hoffmann et al., 2014) and the PRISMS taxonomy of SM Support (Pearce et al., 2015). However, it could be suggested that these frameworks presented particular limitations to mapping out the intervention. For example, the PRISMS taxonomy of self-management support (Taylor et al., 2014; Pearce et al., 2015 was derived from over 100 systematic reviews of self-management support (Pearce et al., 2015) with a range of different long-term conditions and is not specific to cancer. Therefore, the broad development base that the taxonomy has been built from has the potential to limit the process of developing an intervention for a specific condition, such as cancer. This limitation and the lack of testing of the taxonomy presents an opportunity for further research and testing to provide new knowledge to this identified gap. In contrast, it could be argued that using the TIDieR checklist and PRISMS taxonomy to develop and design the intervention may have made the intervention too prescriptive and therefore wider applicability may present issues. However, it is suggested that the valuable lived experiences of peers, that have influenced the intervention content, bring a sense of belonging and normality in line with wider studies (Cramer et al., 2014; Dickerson et al., 2011; Gooden & Winefield, 2007; Oliffe et al., 2010; Sullivan, 2003). The intervention's strengths-based approach aims to increase men's self-efficacy to self-manage during the cancer early detection period, and value the skills they have to cope effectively. Therefore, in terms of the effectiveness of the intervention, future studies have the opportunity to measure baseline scores of distress and wellbeing which may help to determine for whom the intervention is most effective in terms of outcome measures. There is scope for the intervention to be evaluated with certain groups of men (identified as higher risk and needing support) to gain the most impact and understand who it works for and under what circumstances. This would allow for additional studies in the field of patient stratification, ensuring it is targeted at those men who need it most.

Limitations of Thesis Findings

Men, like women, are not a homogenous group and, as acknowledged in this thesis, it is important to recognise the diversity, variety and different needs, preferences and perceptions between men. Therefore, caution is needed when interpreting and generalizing the findings reported in this thesis, for several reasons. A total of 33 participants were included across three studies (four participants were involved with two of the studies). Participants were recruited via community links and networks, and self-selected to be part of the research. Studies contained men who had expressed an interest in the research, and it is possible that men with an active interest in self-management or cancer research may have been more likely to participate. Further research needs to explore how best to engage a wide range of men during the early cancer detection period, to inform and build on the limited existing research. Further studies need to ascertain what the most effective methods are to engage men in early cancer detection research, and under what circumstances. Being able to evaluate the effectiveness of engagement methods will provide cancer researchers with valuable insight to develop their recruitment techniques and optimise opportunities for their research.

The sample sizes of the studies were small and, despite some purposive sampling, most participants were White British and not representative samples of the UK-based population undergoing testing during the early detection period. Previous research has demonstrated that men from Black Asian Minority Ethnic (BAME) communities experience cultural issues in relation to cancer screening (Johal, Shelupanov, & Norman, 2012) and encounter stigma when seeking help (Wilkins, 2013), with more fatalistic attitudes towards cancer. As such, a limitation of this research is that the needs of men from protected groups (who may have different specific needs) are not reflected within the studies (due to the low numbers of participants included from these communities). Therefore, further research, with larger cohorts of men from protected characteristic groups (such as BAME or GBTQ+ communities), needs to be conducted to test the applicability of these findings. Additional study sample limitations should be noted. For example, participants in the prioritisation study (in Chapter 4) had exclusively been diagnosed with prostate cancer; and most participants in the DST study (in Chapter 5) had been diagnosed with cancer. Therefore, the findings and proposed intervention are built on the understanding from the groups of men included in the studies. Further research studies, undertaking similar studies with larger cohorts of participants, maybe beneficial to test the replicability of findings. In particular, a larger cohort could consider the potential to stratify men during the cancer early detection period, in order to identify and prioritise those with unmet needs and most likely to have significant problems in the future (referred to as ‘risk stratification’) based on demographics and circumstances. The exploration of mediating factors could also include understanding the role of factors from the Transactional model, such as coping and appraisal.

A mixture of approaches were used in the collection of data using qualitative and quantitative methods, in combination and separately, across the studies. The methods chosen for each study presented certain limitations to the findings. The use of semi-structured telephone interviews in Chapter 2 offered a good geographical reach of participants, but limited the observational visual cues and reading of participants’ body language, which may have provided further information (Opdenakker, 2006). In addition, the method choices for each study may have affected the recruitment of participants. For example, the modified NGT approach taken in Chapter 4 was communicated as a group workshop, and subsequently may have consisted of individuals who were more comfortable participating in a group format than other men. Similarly, using a different method, such as a survey, may have attracted a different type of individual, as preferences vary depending on the subject (especially as this topic was deemed to be sensitive). Further research needs to explore how best to collect the experiences of men during the early cancer detection period to inform intervention development. This research has been useful in highlighting a range of different methods with varying degrees of effectiveness. Further studies need to ascertain what the optimal methods are to engage men, under what circumstances, during this period. Being able to evaluate and understand these differences will provide future researchers with valuable insight to advance their research.

In addition, the researcher's role and position is central to the research process (Demery, Thirlaway, & Mercer, 2012), and using a different method to prioritise the themes may have resulted in a different type of relationship between participants and the researcher, influencing the findings (see 'Reflexivity' section below) (Demery, Thirlaway, & Mercer, 2012; Jootun, McGhee, & Marland, 2009; Mays & Pope, 2000; Murphy et al., 1998). In addition, using digital story telling as a way to collect data is new and emerging, but the participatory nature of the method may have presented a barrier to participation for some men. The World Health Organisation 'Strategy on the health and well-being of men in the WHO European Region' (WHO, 2017), which aims to improve men's health, recognises the need to engage men through participatory approaches, across communities, in order to achieve sustainable results. A focus is given to the need to utilize digital health, through new and innovative applications of technology, to overcome the social and practical barriers men experience. Therefore, in line with this strategy (WHO, 2017), the findings from this research and the limitations outlined above, future research aimed at engaging men should consider adopting a targeted approach that incorporates conceptions of masculinity and offers a wider range of participatory method approaches.

The retrospective nature of the research may have affected the accuracy and recall of events, information, identified needs and experiences. Recognised in Chapter 1, there is limited research that has been conducted with men going through the early cancer detection period, at a number of different time points, and future research should consider addressing this identified gap. Further research would benefit from recruiting participants during the period from testing to receiving the test results. By targeting recruitment in this way, value would be gained from understanding the cancer early detection period and participants' identified needs. However, ethically it may prove to be more difficult due to a potentially higher risk of distress whilst awaiting diagnostic confirmation.

The Transactional theory of stress and coping (Lazarus, 1999; Lazarus & Folkman, 1984) underpins the intervention and has been used as a theoretical basis, throughout the studies, as it has with other studies on cancer (Garrett et al., 2013; Halstead & Fernsler, 1994; Parle & Maguire, 1995; Reynolds et al., 2000). The theory has provided a generic framework for the studies - and specifically the intervention - around adaption and coping, bringing with it a valuable empirical foundation (Garrett et al., 2013; Halstead & Fernsler, 1994; Parle & Maguire, 1995; Reynolds et al., 2000). Although not cancer specific the model incorporates the adjustment and readjustment, that men experience during the early detection of period of cancer when undergoing exploratory procedures (emotional adaptation and re-adaption). However, an identified limitation of the model, within the cancer specific context, is it that the complexities of the model at the macro level needs further empirical testing and development (Hulbert-Williams et al., 2013). However, the model has allowed for the incorporation of special conditions that are involved with men waiting for cancer test results. Future testing of the intervention offers the opportunity to contribute to further empirical testing and development of the model at a macro level.

Lastly, as referred to above, the experience and skill of the researcher conducting the research will have had an impact on each stage of the research process; from choosing the right methodology, recruiting participants, collecting data, interviewing participants, analysing data, and collating the findings. The position and stance of the researcher may have influenced and limited the exploration of issues, which will now be discussed in more detail within the section on reflexivity.

Reflexivity

The researcher’s role and position is central to the research process and can have an impact upon the interpretation of the methods, concepts and analysis of findings (Demery, Thirlaway, & Mercer, 2012), particularly within qualitative studies (Jootun, McGhee, & Marland, 2009; Mays & Pope, 2000; Murphy et al., 1998). Tong, Sainsbury and Craig (2007) suggest reporting the researcher’s characteristics and their relationship to the participants, as it may add clarity to how they may have influenced findings. Therefore, it is important and necessary for the researcher to explain in detail their own characteristics, feelings, and expectations to enable the examination of prior preconceptions that may influence or determine focus on issues, and on the interpretation of participants’ accounts (Shaw, 2010).

Recognising the importance of beliefs and biases early on in the research process allows for the researcher position to be understood and then ‘bracket or suspend those researcher biases as the study proceeds . . . individuals reflect on the social, cultural, and historical forces that shape their interpretation’ (Creswell & Miller, 2000, p. 127). In recognition of the need to suspend and mitigate the preconceptions that I had as a female researcher investigating men’s experiences, a number of bracketing methods were used to prevent tainting the research process (Tufford & Newman, 2010). This included the use of a reflexive diary in which I detailed my thoughts, feelings, reflections and choices as I progressed chronologically through the studies. Extracts from the diary are included below to illustrate a number of reflections, and preconceptions during the research process and how those changed over time.

As I have worked in the development of cancer services for several years and, although not a registered healthcare professional, have worked in the NHS and national cancer charities for over 20 years, I expected that the recruitment to the empirical studies would be relatively easy, due to the networks and relationships I had already built within the sector. Generally, as a certain amount of rapport and trust was already built, the relationships supported the recruitment process to all the empirical studies. However, it is acknowledged that the researcher’s values and assumptions will influence the way in which data is collected (Mays and Pope 2000), and although recruitment to the studies was relatively easy it resulted in introducing several unanticipated limitations on the research. For example, a number of the participants had met me before, during different events related to my occupation and, as acknowledged, this may have introduced self-selection bias into the recruitment process. During the first few interviews, with those who had met me before, participants made inferences and references to information about their circumstances without fully expanding or providing in-depth detail during the interview. Initially I failed to recognise this quickly, and did not proactively prompt, and probe accordingly. This is recognised as a `taken-for-granted' perspective which can occur when a researcher, familiar with a participant’s social world, omits questioning areas that are self-evident (McEvoy, 2001). Upon reflection, whilst writing in my reflective diary, and listening to the interviews on the Dictaphone, I recognised this omission and decided to take action and add prompts to mitigate this further. Consequently, subsequent interviews were started by me clearly stating that no assumptions should be made about my knowledge of their past experiences – or circumstances – and gave reassurance that I was interested in their experiences of the early cancer detection period and the circumstances that surrounded the period.

Another reflection, identified early in the research process, was with regards to my role as a female researcher conducting research with male participants. It is recognised that the gender of the researcher, and participants, is likely to affect the information shared within the interview, as the participants will taper their opinions and present responses within a gendered context (Schwalbe & Wolkomir, 2001; Williams & Heikes, 1993). Prior to commencing the studies, I naïvely believed that my gender would not impact significantly on participants' responses to the questions posed. However, after the first couple of interviews I began to recognise how the gender difference may affect the participants' responses in different ways. For example, several participants were keen to point out to me that although they recognised that 'other men' may need emotional support during the early cancer detection period (and acknowledged the importance of it with the cultural shift needed to 'normalise' it within society), they had been 'OK' (i.e. not needing emotional support). Not disclosing vulnerability and shielding from perceived weakness has been recognised as a key aspect of hegemonic masculinity (Connell 1995). It may be argued that the presence of an educated middle-class woman, with no personal cancer experience, had an effect upon on men's responses, as they felt unable to disclose their emotional needs due to a need to preserve their masculinity (perceived emotional stability and strength). In recognition of the need to suspend and mitigate the preconceptions that I had, an extract below from the reflexive diary illustrates some of my thoughts during the interview stage, particularly around the issue of disclosure and burden, and the impact on me as a researcher:

> *I've just finished another telephone interview. The last couple of interviews have included some horrific stories of what men have had to go through during the period and I feel quite low and sad. I wasn't really expecting to feel like this as I speak regularly to people who have been affected by cancer. Perhaps it could be because some of them have spoken about dealing with issues on their own, without support from others? A few of the men spoke to me about how they guarded communications with their family in a way to protect them.*

Previous research has suggested that male participants, being interviewed by female researchers, may curtail their language to ensure they do not offend the researcher (Williams and Heikes, 1993). Although it is difficult to know whether participants altered their language because I was female, as numerous participants used expletives during the interview process, it is unlikely that this was the case for all the participants. In contrast, over time I recognised how being a female researcher interviewing male participants may have benefitted the richness of the data findings because as the interviews progressed, and I became more relaxed, many participants talked freely about sensitive issues, such as sexual difficulties, suicide and depression. An excerpt from my diary illustrates my reflections, after the prioritisation workshop, at the time:

> *I'm starting to question how the men viewed me, a relatively young woman asking them questions about their thoughts and feelings during a time of uncertainty and anxiety. They seem to talk quite openly and freely about all sorts of different topics including erectile dysfunction and robotic knives! Many of them know that I work for a large cancer charity, so I wonder how much of their willingness to talk is because of this?*

It is possible that the strategies implemented, such as: purposely not asking specific questions about gender; masculinity; or their experience as a man may have also facilitated the process. These strategies have been highlighted as successful strategies to use when conducting research with men (Oliffe & Mroz, 2005). The strategies may have added to creating a safe space for disclosure. Participants may have not been as open about these issues if they felt that they had to conform to masculine traits because the researcher was male.

What the findings add to existing Health Policy

Providing self-management support is one way of effectively managing the global burden of long-term conditions such as cancer (Secretary State for Health, 2006; US Department of Health, 2010; WHO, 2002). The World Health Organisation recently published a draft 'Strategy on the health and well-being of men in the WHO European Region' (WHO, 2017). The strategy outlines a gendered approach to better health outcomes, and efforts, to improve gender equality in health. The goal of the strategy is to improve men's health and well-being through approaches that are driven by equity and are gender-responsive. The drive is to transform the gender roles, structures and norms that expose men to risk factors and act as a barrier to equality and equity in health outcomes across Europe (WHO, 2017). The strategy recognises the need to engage men, through participatory approaches, across communities in order to achieve sustainable results. It calls for recognition of the different health needs and health-seeking behavioural patterns of men, and the need to make health and social services more accessible and appropriate by reaching out to men. A focus is given to the need to utilize digital health, through new and innovative applications of technology, to overcome the social and practical barriers men experience. The strategy recognises the need to build on lessons learned from digital health initiatives, that address men's specific needs (such as mental health and well-being) using gender and social determinants of health approaches. Therefore, in line with the strategy (WHO, 2017), it could be suggested that some of the evidence in this thesis demonstrates the need to have a specific targeted approach to reach men that incorporates, and is related to, conceptions of masculinity, since some links were found between communication tensions, issues of masculinity, and the impact on participants' experience. The evidence suggests that valid justification for obtaining support needs to be clear and framed in a way that encourages men to view sources of support and resources as building blocks, to enable them to look after others around them. For example, there should be clear messaging to communicate that by taking care of their own needs they are better able to protect the more vulnerable they look after i.e. 'doing it for others'. This research adds some weight to the opportunities that exist to work with men to build skills earlier on in the cancer trajectory. Recognised in the behaviour change field as a 'teachable moment', this research contributes limited evidence that suggests the diagnostic period is a prime opportunity for intervention as men welcome appropriate support that provides them with a sense control and independence (to have choice and make changes).

Recently, the National Cancer Transformation Board outlined a range of steps designed to support early detection, speed up diagnosis and improve the experience of patients in the published 'Achieving World Class Cancer Outcomes: Taking the strategy forward' (NHS England, 2016). The strategy outlined the introduction of a new 28-day faster diagnosis standard, created to guarantee that patients wait no longer than 28 days for their results. Full uptake of the standard is expected by 2020 (NHS England, 2016a, 2016b). In 2015, NICE introduced new guidance (NG12) (NICE, 2015) for the management of suspected cancer on the urgent 2 week wait (2WW) cancer referral pathway; included in the updated guideline is the recognition of the lack of current research on patient information needs and experience throughout the cancer diagnostic pathway. It recognises that filling the gap should improve future patient experience, and calls for more qualitative studies to be published to highlight the need to identify the key issues in patient experience and information needs in the cancer diagnostic pathway (NICE, 2015). In line with the recognised deficit in the NICE (2015) guidelines, the evidence presented through this doctoral work offers a small but valuable contribution to inform early detection guidelines and policy about the experiences of men during the diagnostic period. A number of the findings may form a basis for further research into:

patient satisfaction and perception regarding the quality of care and information, and; issues related to quality of life.

What the findings add to Healthcare Practice

Healthcare professionals are well placed to listen and understand the experiences of men during the cancer early detection period, and the evidence (Chapter 4) suggests one of the highest prioritised needs is effective communication with them. To aid clarity of understanding, and effective communication, findings suggest the need for healthcare professionals to use plain English, including the word 'cancer'. Although this clarity of communication is well evidenced in the literature (Head et al., 2012; Kazimierczak et al., 2013; McClain, 2012;), some of the findings from the accounts (in Chapter 3) confirm that this is not standard practise across professionals in health and cancer services. In the qualitative empirical studies, men recalled the use of words such as 'mass' or 'lesion' which led to confusion and delay in understanding they had been given a diagnosis of cancer. The limited evidence suggests effective communication with healthcare professionals to improve understanding at diagnosis. This mirrors previous studies (Arrington, Grant, & Vanderford, 2005; Bourke et al., 2012; Oliffe, 2005; Sullivan, 2003) and adds to the current research. Some of the findings confirmed HCPs' (Health Care Professionals) difficulties in communicating bad news and acknowledged how some professionals need to disconnect emotionally to be effective. This builds on other studies' findings (Dennison, 1995; Kruijver et al., 2001) which refer to 'blocking' behaviour used during emotionally charged interactions as a defence mechanism to enable coping and preservation of emotional wellbeing. This raises suggestions for further learning and development for a number of HCPs working with men during the cancer early detection period. The evidence suggests that if a diagnosis is given, a number of men want factual, to-the-point confirmation with the opportunity to talk about the results. It is implied that a sense of control is enabled when there is time to question and explore issues with the healthcare professional, leading to feeling more confident and informed.

The findings suggest that men want a positively-framed prognosis that delivers hope for the future with tailored information which instils confidence, reassurance and hope (delivered directly to them in a way that is supportive and compassionate). This adds to previous research that suggests the importance of giving individuals as much information as they would like, allowing time for discussion, and presenting the information clearly (London Cancer Alliance, 2014; Schofield et al., 2003). The empirical studies tentatively highlight the need and importance placed on quality tailored information. Men wanted to access information and support independently, highlighting the internet as their ‘first port of call’, but a barrier to this was a lack of confidence in deciphering the credibility of sources. The opportunity exists for healthcare professionals to signpost men to quality sources of information and support during the cancer early detection period, to enable effective self-management. These limited findings have some implications for workforce within diagnostic cancer services, consultation appointment times, and the skills of the healthcare professionals to manage the consultation effectively (refer to Table 19).

Table 19 - Implications and recommendations			
		Implication	**Recommendation**
Practice	1	Fluctuating distress can be experienced during the cancer early detection period and some men want support to be able to cope and self-manage independently.	Men should be routinely signposted to self-management support during the cancer early detection period to enable them to cope and self-manage independently.
	2	Interventions introduced during the cancer early detection period appear to not cause anxiety, can reduce it, and may prepare men for diagnosis. Currently no evidence-based online self-management support interventions exist for men to use during the cancer early detection period.	The online 'Men in Limbo' intervention presented in this research could be tested to explore support for men to enable them to access self-management support during the cancer early detection period.
	3	It is suggested that some men have a number of shared psychosocial needs and experiences during the period with some of the greatest needs relating to the ability to plan, have effective communications with healthcare professionals, and gain social support. Some men have current unmet needs relating to connectivity with other men's experiences (to bring a sense of meaning, shared information and encourage positive coping strategies) and emotion management (particularly anxiety and uncertainty).	Men should be able to access support that enables them to manage anxiety and uncertainty during the cancer early detection period. It is recommended that they should be provided with the opportunity to access other men's experiences to connect, share information and encourage positive coping strategies. The digital stories presented in this research could provide a key component that can be either used in conjunction with the 'Men in Limbo' intervention or as a stand-alone resource.
	4	Some men want to access information and support independently; however they may need support to navigate to credible tailored information sources. The internet is identified as a 'first port of call' however, some men lack confidence in deciphering the credibility of online sources.	Healthcare professionals require information and knowledge about high quality online information and support to signpost men to during the cancer early detection period to enable them to self-manage effectively.
	5	Some men place high value on social support, which provides emotional support to cope and manage thoughts, feelings and uncertainty during the cancer early detection period. Men are unlikely to seek help when disconnected or isolated from key constructs, therefore those who are single, widowed, or separated - with a lack of a social support network – may be at greater risk of distress during the period.	Healthcare professionals should be aware, and mindful, that men who are socially isolated during the cancer early detection period may have additional unmet support needs compared with men who have access to a good social support network.
	6	A number of men prioritise the need for effective communication with healthcare professionals during the period and want a positively-framed prognosis that delivers hope for the future with tailored information which instils confidence, and reassurance. When medical terminology is used, and plain English isn't, it can lead to confusion and a delay in understanding when a diagnosis of cancer is delivered.	Healthcare professionals (HCPs) are well placed to listen and understand the experiences of men during the period. It is suggested that it is important for HCPs to give each individual as much information about the diagnosis as desired, providing written information, allowing time for discussion and presenting the information clearly. HCPs should have access to advanced communication training to support the facilitation of effective messaging and breaking bad news.

	7	The expectations of ‘being a man’ impacted on a number of men’s perceived experiences of the period, and effective communications with healthcare professionals made a positive difference to their perceptions and subjective wellbeing.	Healthcare professionals (HCPs) should be made aware of the way in which issues of masculinity can impact on men’s perceptions and wellbeing during the period. Dissemination of the research findings should include ways to reach HCPs to make them aware of the vital role they play in supporting men to understand and manage expectations, through positively framed consultations.
	8	A number of men are unsure where to look for information and support, and how to assess its credibility.	Healthcare professionals (HCPs) should have access to credible sources of information and support to be able to signpost and refer men to during early detection consultations.
	9	Online evidence-based interventions offer some men an option, and a potential solution, that fits with their need for anonymity and flexibility to access support at a time that is appropriate for them.	Healthcare professionals (HCPs) should be made aware and have access to credible sources of online evidence-based interventions to refer men to during consultations.
Policy	10	Some men want to support other men. In order to encourage men to view sources of support and resources as relevant for them and as ‘building blocks’ (to fulfil that supportive role for others) the justification for obtaining support needs to be clear and framed explicitly illustrating the connection.	Men need clear messages that communicate the connection between taking care of themselves and the improved ability to support others i.e. ‘doing it for others’.
Research	11	Some men are willing to be involved with creative ways to share their experiences and provide support for other men. The participatory process of developing peer digital stories is acceptable, and valuable, to some men providing multiple benefits.	Creative methods are useful when engaging some men in a co-design process and can be used effectively to understand lived experiences and provide beneficial outcomes.
	12	Co-design methodologies can enable the articulation, and transformation, of the cancer early detection period. They can offer a way for men to connect with their experiences, rather than just explaining them, giving greater benefit.	More research is needed to understand the potential impact of using creative, co-design, methodologies with men.
	13	Interventions developed to support men during the cancer early detection period should build on men’s identified strengths; encourage self-management of distress, and; enable effective coping during the period.	Future interventions should target men during the cancer early detection period and could build on the findings from the empirical studies in this research.

Future research

Based on the findings and evidence presented, there are several recommendations for future research. As highlighted by NICE (2015), and the findings in Chapter 1, there has been limited research into the experiences of patients during the cancer early detection period. The findings here represent a starting point and can contribute towards future empirical studies into the gendered cancer early detection period.

Early intervention and impact

Distress during the cancer early detection period is currently not measured or collected routinely, and there is not a robust evidence base for the prevalence of distress in men during the period. Apart from a small number of studies (Dale et al., 2005; Fantini-Hauwel et al., 2011; Liao et al., 2008), there is low level knowledge about the impact distress has on individuals and how that affects outcomes at the point of diagnosis, throughout the treatment phase and into the survivorship stage. The suggested link between distress and outcomes (Montgomery & McCrone, 2010; Widerman 2004; Drageset & Lindstrøm, 2005; Zhu et al., 2018) warrants further investigation for several reasons. This ‘unknown’ cohort of men living with heightened levels of anxiety may face long-term implications of distress. Early identification provides opportunities to enhance further screening adherence (Paskett, Harrop, & Wells, 2011) and patient experience (De Silva, 2011; Knapp, McDaid, & Parsonage, 2011; NICE, 2015; Paskett, Harrop, & Wells, 2011). This particular area of research – more commonly reported on in women’s cancer studies (Montgomery & McCrone, 2010) – may help to determine those at risk of higher levels of need further on in the cancer trajectory. The ability to predict men who may experience higher levels of distress offers an opportunity to influence better decision-making and potentially treatment outcomes, thus affecting clinical outcomes and health economics (De Silva, 2011; Knapp, McDaid, & Parsonage, 2011; Paskett, Harrop, & Wells, 2011). The measurement of distress, consistency between the methods used in studies, and multiple measurement points (at more than one time point) are all suggested areas for future consideration to understand fully the impact distress has during the period. The findings from the literature identified certain groups of men who may be at higher risk of experiencing distress due to their characteristics or circumstances. There is potential for future research to explore and understand in more detail the experiences of men from protected characteristics groups. This includes identifying any different prioritised unmet needs and coping strategies. These findings could then be mapped to identify the differences and so source effective bespoke intervention components.

Insight into the effective components of interventions that support the management of distress were touched on in the systematic review (Chapter 2). The review evidenced some limited short-term impact that health education can have in providing effective knowledge for those who go on to receive a diagnosis of cancer, and can engage, prepare and inform men to manage uncertainty). However, it highlights the need for further longitudinal research to explore and understand what aspects of health education interventions are effective, with which men, from the early detection period through to the survivorship stage. It could be hypothesised that if men are provided with the right information and support earlier on in their cancer journey, there is more opportunity to influence positive self-management and coping during the period. Essentially does earlier, ‘upstream’, support have the potential to affect ‘downstream’ outcomes? There is potential for future studies to extend the knowledge of opportunities to stratify men during the period to understand how to gain better long-term outcomes for men with different characteristics.

Value was given to some strategies that aided feelings of being in control, and to activities that provided meaningful distraction, such as work (which brought purpose and status). By aligning the intervention with ‘productivity’ and ‘helping others’, it could be suggested that it will appear more acceptable to the future targeted population. There is scope to understand in greater detail how this alignment could be changed to appeal to different groups and communities of men.

Impact and outcomes of connecting men with peers during the cancer early detection period

Social support is widely recognised as enabling coping during times of stress and disruption (Aneshensel, 1992; Dohrenwend, 2000; Pearlin, 1999). Some of the findings from this thesis confirm the high need for social support during the cancer early detection period. A number of men with good social support have been found to have, in general, better health-related quality of life, coping skills and self-management ability (Kershaw et al., 2008; Scholz et al., 2008). Chapter 1 identified that men are unlikely to seek help when disconnected or isolated from key constructs, as routines and contact provide stability and act as a buffer against isolation (Berger et al., 2012). Therefore, it could be suggested that men who are socially disconnected or isolated could be at greater risk of distress during the cancer early detection period.

This thesis has provided some further evidence of the value men place on hearing and sharing experiences during the period. Previous research has identified that individuals want to reduce their fears and increase their confidence (Lowe et al., 2009), and alter the appraisal of the illness (Zufferey & Schulz, 2009), by hearing from peers who have successfully faced similar situations (Herxheimer et al., 2000). Participants within the empirical studies communicated a desire to ensure future men learnt from their experiences and benefitted from a ‘shared belonging’ which targeted populations of men could relate to. The peer support elements of the online intervention provide opportunities for reflection, encouragement and constructive challenge. Some of the participants wanted to give men the chance to connect with other men’s thoughts and feelings through the digital stories, whilst preserving anonymity and acknowledging issues of male identity that are important to them. The space for social comparison is created, whilst still acknowledging the reluctance to seek support. There is opportunity to further explore the impact that the online intervention has on the cancer early detection period for those who are socially isolated or disconnected, and scope to understand what support is needed to improve the experience of the waiting period.

Strengths of the research

The focus of the studies was on men who had lived experiences of the cancer early detection period, with multiple diagnostic outcomes. A major strength of the thesis is the approach used to emphasise the central part played by the ‘voice’ of the lived experiences of men who had been through the cancer early detection period. The methodology chosen throughout the empirical qualitative studies enabled this approach. The interviews conducted, prioritisation of needs workshop and co-designed digital stories enabled an original contribution to knowledge of men’s experiences of the period. The novel approach of co-designing digital stories to capture men’s experiences and create a resource for further implementation is unique within the cancer early detection period. The stories highlight important aspects chosen by the participants in collaboration with the researcher. As the stories were co-designed with participants, in line with recent research (Ellis et al., 2012; Ellis et al., 2013), they are more likely to be successful in engaging future men. No study to date has conducted work with men during the period, across tumour site screening, with multiple diagnostic outcomes.

Another major strength of the research is that it illustrates to future researchers the willingness of male participants to engage in a co-design process where they can see the value of their contribution. The participants were keen to ‘give back’, to help other future men, giving up their time freely. This willingness of men to co-design solutions illustrates the potential for future opportunities to build on and broaden similar approaches targeting men. This is particularly important in light of the finding that men are more likely to accept help to self-manage if framed within the context of 'helping others' (Galdas el al, 2014) or facilitating 'productivity' (as outlined in Chapters 1 and 5).

Another strength of the research is that it has drawn from studies from across several disciplines. The wider context overview, in Chapter 1, collated multidisciplinary studies to illustrate the impact of the cancer early detection period on men. Building on the overview, the systematic review (Chapter 2) allowed for a comprehensive approach to identify, appraise and synthesize the limited number of relevant intervention studies. This approach has given a firm and robust foundation to the thesis by highlighting the gaps in knowledge and empirical work conducted to date. By using this set methodological approach, assurance is given to future studies building on the review's conclusions. By minimizing bias, other future researchers can conclude reliable evidence from the findings.

This thesis has produced a comprehensive account of the complex issues related to addressing the needs of men during the cancer early detection period. The multiple methods collated the evidence, which was then developed into the 'Men in Limbo' online intervention (outlined in Chapter 6). Built from a needs-led approach, underpinned by theory and a robust evidence base, it provides a meaningful and purposeful intervention to support men during the cancer early detection period. The research offers the first online self-management support intervention of its kind to address the unique needs of men during the cancer early detection period.

Conclusion

This thesis has documented the process of undertaking a mixed methods systematic review and empirical qualitative studies to explore and provide evidence of the experiences and unmet needs of men during the cancer early detection period. In answering the questions posed, the studies have identified some priorities and gaps to address the needs of men to self-manage effectively during the cancer early detection period. By taking this approach, the thesis has highlighted a number of opportunities for future research, policy and practice.

This research adds some insight to the currently limited research on the cancer early detection period. Experiences during the cancer early detection experience affect both the diagnosis, and post-diagnosis, periods. As cancer incidence rates rise – and the number of men living with uncertainty and anxiety increases – there will be a rise in men needing support to manage distress. Therefore, by addressing unmet needs earlier on in the cancer trajectory, this research has highlighted the potential areas to make a small but positive impact to minimise distress and improve the experiences during the period, and further down the cancer trajectory. During the cancer early detection period, some men said that they wanted support to: navigate to credible tailored information sources; connect with other men's experiences (to bring a sense of meaning, shared information and encourage positive coping strategies), and; independently manage their emotions (particularly anxiety and uncertainty).

Future work needs to consider the potential to stratify men during the cancer early detection period, in order to identify those who are at heightened risk of distress, unmet need and most likely to have significant problems in the future (referred to as 'risk stratification'). This thesis has provided some limited evidence for the impact and value of social connectivity, as men suggested that being connected was related to better management of emotions and perceived ability to cope effectively. Access to a supportive individual can help to alleviate distress and peer support can improve confidence and give reassurance. Some men value the lived experiences of their peers, and the opportunity to share with others can bring a sense of belonging and normality. It could be argued that some men who are socially isolated are at heightened risk of distress and may experience additional unmet needs during the period.

A number of effective problem-focused and emotion-focused coping mechanisms (such as planning, distraction and humour) supported adaption to the threat of illness and helped to alleviate some of the anxiety experienced, providing a feeling of being more in control and confident to cope. The integration of the digital stories within the intervention could provide a forum to communicate experiences and encourage other men to find effective coping strategies that align with their identity, enabling better management during the period. Therefore, building on the limited findings from this work, there is the opportunity for future research to enhance patient experience, with the potential to affect clinical outcomes and health economics for certain male groups.

Research regarding men's experiences of the cancer early detection period is in its infancy. The findings in this research highlight how cancer early detection services, and healthcare professionals, should consider further how they engage with men during the period and how support could be aligned with masculine values. It could be suggested that future service developments and interventions proposed to support men during the period should build on a number of the key findings in the empirical studies. By providing support to enable men to cope effectively, and manage anxiety independently, it could be argued that they may be more likely to feel prepared, and in control, if a cancer diagnosis is given. Managing expectations and preparing men may support a better quality of life during the cancer early detection period.

The findings contribute to the limited existing research within the cancer early detection field, and it could be suggested that the next steps should build on the foundations that this research has provided, to disseminate the findings and provide a voice for a number of unheard men. There is potential value in the outlined 'Men in Limbo' intervention as it builds on the strengths men already have and acknowledges the expertise (by experience) that they bring. It could be argued that by providing user-led interventions and resources to support the reduction of distress and uncertainty experienced, enables men to cope and manage independently, future men can be spared feeling like they are '*going into a darkened room, and shutting the door*' (P12, Ch3).

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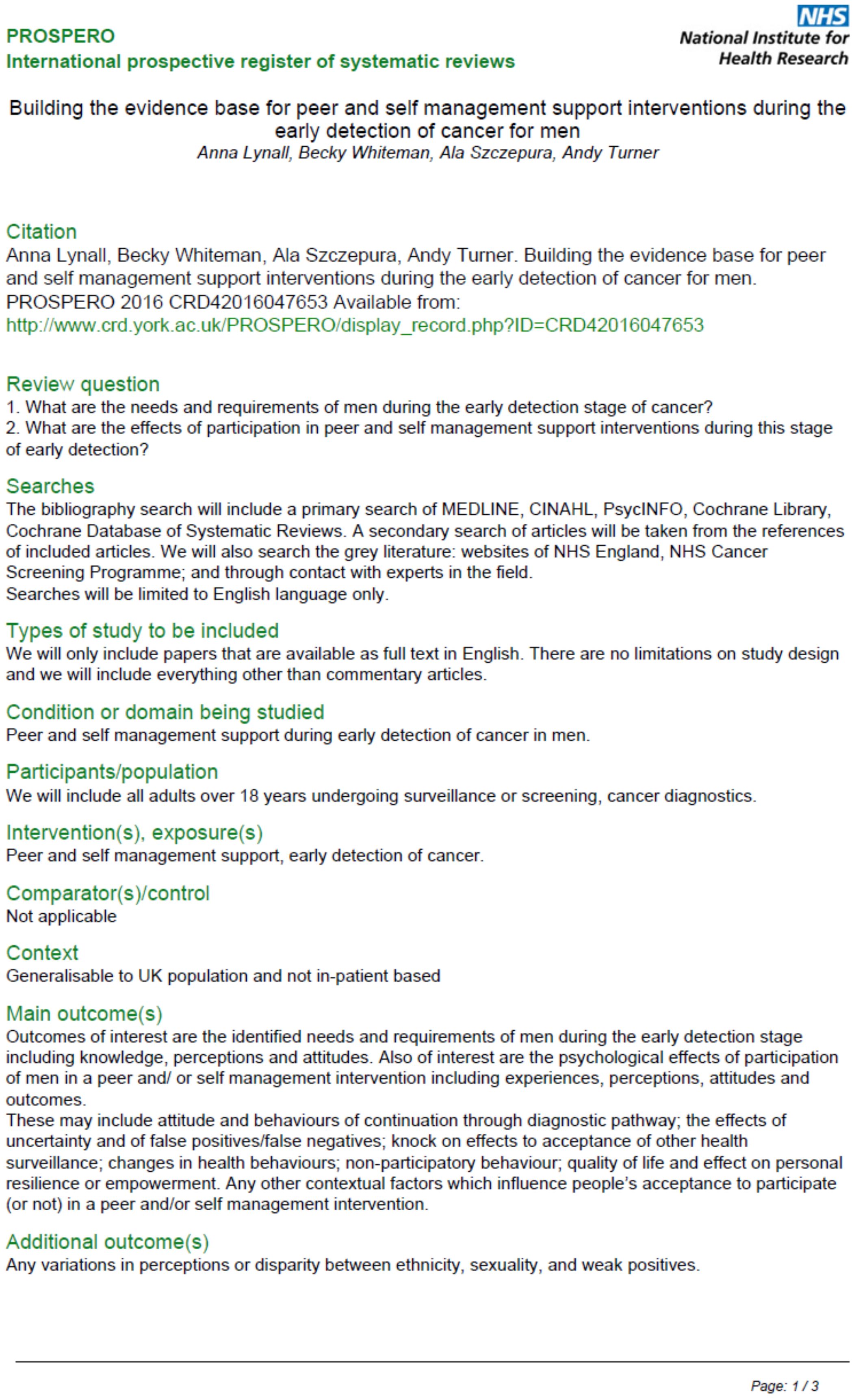
Appendices

Appendix 1 – PROSPERO Record



PROSPERO
International prospective register of systematic reviews

NHS
National Institute for
Health Research

Building the evidence base for peer and self management support interventions during the early detection of cancer for men

Anna Lynall, Becky Whiteman, Ala Szczepura, Andy Turner

Citation

Anna Lynall, Becky Whiteman, Ala Szczepura, Andy Turner. Building the evidence base for peer and self management support interventions during the early detection of cancer for men. PROSPERO 2016 CRD42016047653 Available from: http://www.crd.york.ac.uk/PROSPERO/display_record.php?ID=CRD42016047653

Review question

1. What are the needs and requirements of men during the early detection stage of cancer?
2. What are the effects of participation in peer and self management support interventions during this stage of early detection?

Searches

The bibliography search will include a primary search of MEDLINE, CINAHL, PsycINFO, Cochrane Library, Cochrane Database of Systematic Reviews. A secondary search of articles will be taken from the references of included articles. We will also search the grey literature: websites of NHS England, NHS Cancer Screening Programme; and through contact with experts in the field.
Searches will be limited to English language only.

Types of study to be included

We will only include papers that are available as full text in English. There are no limitations on study design and we will include everything other than commentary articles.

Condition or domain being studied

Peer and self management support during early detection of cancer in men.

Participants/population

We will include all adults over 18 years undergoing surveillance or screening, cancer diagnostics.

Intervention(s), exposure(s)

Peer and self management support, early detection of cancer.

Comparator(s)/control

Not applicable

Context

Generalisable to UK population and not in-patient based

Main outcome(s)

Outcomes of interest are the identified needs and requirements of men during the early detection stage including knowledge, perceptions and attitudes. Also of interest are the psychological effects of participation of men in a peer and/ or self management intervention including experiences, perceptions, attitudes and outcomes.
These may include attitude and behaviours of continuation through diagnostic pathway; the effects of uncertainty and of false positives/false negatives; knock on effects to acceptance of other health surveillance; changes in health behaviours; non-participatory behaviour; quality of life and effect on personal resilience or empowerment. Any other contextual factors which influence people’s acceptance to participate (or not) in a peer and/or self management intervention.

Additional outcome(s)

Any variations in perceptions or disparity between ethnicity, sexuality, and weak positives.

Data extraction (selection and coding)

We will first perform a calibration exercise to ensure reliability of screening. Two reviewers will independently screen a small subset of citations (circa 100) using the inclusion/exclusion criteria. These will be reviewed as a group with other members of the research team until consensus is met and inclusion/exclusion are refined as necessary. Once consensus has been met, two reviewers will independently review all titles and abstracts and code against a pre-defined criteria (level 1 screening). Conflicts will be resolved through review as a group with other members of the research team until consensus is met. In level 2 screening, two reviewers will independently review full text articles, code and gain consensus as per level 1 screening. Two reviewers will abstract data independently using a standardised data extraction table. The data extraction table will be piloted on a small subset of articles (circa 10) and modified accordingly, until consensus is met.

Risk of bias (quality) assessment

Two reviewers will independently assess the quality of included studies using a validated quality assessment criteria tool. A third reviewer will be available to settle discrepancies between reviewers.

Strategy for data synthesis

No meta-analyses are planned. The results will be tabulated for consideration by the research team and the Early Cancer Detection Consortium. A narrative synthesis is planned.

Analysis of subgroups or subsets

In addition to the main analysis, it is anticipated that there will be subset analysis of different population subgroups within the evidence ie Gay, Bisexual and Transgendered and Black, Asian and Minority Ethnic (BAME) populations.

Contact details for further information

Mrs Lynall
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Organisational affiliation of the review

Coventry University and UK Early Cancer Detection Consortium
www.coventry.ac.uk

Review team members and their organisational affiliations

Mrs Anna Lynall. Coventry University
Ms Becky Whiteman. Coventry University & University Hospitals Coventry & Warwickshire NHS Trust
Professor Ala Szczepura. Coventry University
Professor Andy Turner. Coventry University

Anticipated or actual start date

14 September 2016

Anticipated completion date

31 January 2017

Funding sources/sponsors

Mrs Anna Lynall is funded through a PhD Studentship from the Centre for Technology Enabled Health Research at Coventry University.
UK Early Cancer Detection Consortium.

Conflicts of interest

None known

Language

English

Country

England

Stage of review

Review_Ongoing

Subject index terms status

Subject indexing assigned by CRD

Subject index terms

Colorectal Neoplasms; Early Detection of Cancer; Humans; Male; Peer Group; Self Care

Date of registration in PROSPERO

13 September 2016

Date of publication of this version

11 April 2018

Details of any existing review of the same topic by the same authors

Stage of review at time of this submission

The review has not started

Stage	Started	Completed
Preliminary searches	No	No
Piloting of the study selection process	No	No
Formal screening of search results against eligibility criteria	No	No
Data extraction	No	No
Risk of bias (quality) assessment	No	No
Data analysis	No	No

Versions

13 September 2016
11 April 2018

Appendix 2 – PRISMA Checklist for the Reporting of the Systematic Review

Prisma (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) checklist for the reporting of systematic review

Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	

Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	

Section/topic	**#**	**Checklist item**	**Reported on page #**
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	

Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	

(Moher et al, 2009)

Appendix 3 – CINAHL search strategy

Searching title and abstract

Interface: EBSCOhost Research database Limiters:	
Subject heading	**Keyword search**
1. Neoplasm/ cancer	1.Neoplasm/ OR cancer OR neoplas* OR onco* OR carcinoma
2. Men/ Men’s Health	2.Men OR male* OR gender
3. Early detection of cancer/ early diagnosis / cancer detection/ cancer screening	3.Mass screening/ OR screen* OR test OR detect* OR mass screening OR cancer screening OR precancer OR early detection
4. Intervention / self care	4.Intervention studies/ OR intervention stud* OR stud* OR strateg* OR initiative* OR behavio* OR Self manag* OR Peer Support OR Psychosocial OR Psychoeducat*OR Self Care OR Navigat* OR Patient Navigat*

Appendix 4 – MAStARI data extraction instrument

JBI Data Extraction Form for Experimental / Observational Studies

Reviewer _ Date _

Author _ Year _

Journal_ Record Number_ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _

Study Method

RCT ☐ Quasi-RCT ☐ Longitudinal ☐

Retrospective ☐ Observational ☐ Other ☐

Participants

Setting ____

Population ____

Sample size

Group A ____________________ Group B ____________________

Interventions

Intervention A ____

Intervention B ____

Authors Conclusions:

Reviewers Conclusions:

Study results

Dichotomous data

Outcome	Intervention ( ) number / total number	Intervention ( ) number / total number

Continuous data

Outcome	Intervention ( ) number / total number	Intervention ( ) number / total number

Appendix 5 – MMAT Mixed Methods Appraisal Tool

MMAT Mixed Methods Appraisal Tool					
Study	**Methodological quality criteria (see tutorial for definitions and examples)**	**Yes**	**No**	**Can't tell**	**Comments**
Zeliadt et al	Are there clear qualitative and quantitative research questions (or objectives*), or a clear mixed methods question (or objective*)?	✓			**75%**
	Do the collected data allow address the research question (objective)? E.g., consider whether the follow-up period is long enough for the outcome to occur (for longitudinal studies or study components).	✓			
	1.1. Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research question (objective)?	✓			
	1.2. Is the process for analyzing qualitative data relevant to address the research question (objective)?	✓			
	1.3. Is appropriate consideration given to how findings relate to the context, e.g., the setting, in which the data were collected?	✓			
	1.4. Is appropriate consideration given to how findings relate to researchers' influence, e.g., through their interactions with participants?			✓	
	2.1. Is there a clear description of the randomization (or an appropriate sequence generation)?		✓		
	2.2. Is there a clear description of the allocation concealment (or blinding when applicable)?	✓			
	2.3. Are there complete outcome data (80% or above)?	✓			
	2.4. Is there low withdrawal/drop-out (below 20%)?			✓	
	5.1. Is the mixed methods research design relevant to address the qualitative and quantitative research questions (or objectives), or the qualitative and quantitative aspects of the mixed methods question (or objective)?	✓			
	5.2. Is the integration of qualitative and quantitative data (or results*) relevant to address the research question (objective)?	✓			
	5.3. Is appropriate consideration given to the limitations associated with this integration, e.g., the divergence of qualitative and quantitative data (or results*) in a triangulation design?	✓			

Wade et al	Are there clear qualitative and quantitative research questions (or objectives*), or a clear mixed methods question (or objective*)?	✓			**50%**
	Do the collected data allow address the research question (objective)? E.g., consider whether the follow-up period is long enough for the outcome to occur (for longitudinal studies or study components).	✓			
	1.1. Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research question (objective)?	✓			
	1.2. Is the process for analyzing qualitative data relevant to address the research question (objective)?	✓			
	1.3. Is appropriate consideration given to how findings relate to the context, e.g., the setting, in which the data were collected?		✓		
	1.4. Is appropriate consideration given to how findings relate to researchers' influence, e.g., through their interactions with participants?		✓		
Chiu	Are there clear qualitative and quantitative research questions (or objectives*), or a clear mixed methods question (or objective*)?	✓			**100%**
	Do the collected data allow address the research question (objective)? E.g., consider whether the follow-up period is long enough for the outcome to occur (for longitudinal studies or study components).	✓			
	2.1. Is there a clear description of the randomization (or an appropriate sequence generation)?	✓			
	2.2. Is there a clear description of the allocation concealment (or blinding when applicable)?	✓			
	2.3. Are there complete outcome data (80% or above)?	✓			
	2.4. Is there low withdrawal/drop-out (below 20%)?	✓			

(Pluye et al, 2011)

Appendix 6 – Thematic Analysis Six Phase Process

Phase 1 – Familiarisation with the data

Each interview was read and re-read again several times to aid familiarisation with the data, and notes of initial thoughts and identified themes were made in the margins on paper copies. The first few interviews were summarised with thoughts on the emerging themes.

Phase 2 - Generating initial codes

The qualitative data analysis programme NVivo 11 was used to assist the analysis of the interview data. After consultation with the supervisory team who read the early interviews, a coding strategy was agreed that incorporated the areas of interest included in the topic guide and the new, emerging themes. The coding strategy was again reviewed after each interview and adapted to include emerging themes. Common to thematic analysis, ‘themes’ refer to the highest-level of coding and ‘codes’ refer to lower-levels of coding that are sub-categories of themes (Braun and Clark, 2006).

Phase 3 - Searching for themes

Using the coding strategy, the transcripts were coded within NVivo 11 into themes. The interviews provided a large amount of data, and this initial coding into broad themes broke down the data into more manageable sections that could then be further analysed. The framework facilitated the organisation and classification of data into emerging themes whilst remaining close to the raw data and its meaning. A framework was created for each theme that emerged from the data.

Phase 4 - Reviewing themes

Quotes from the transcripts were inserted into the framework that captured interesting or significant events in the data. The transcripts were reviewed as new themes emerged, and they were coded appropriately to ensure relevant information had been included and the iterative process continued. Immersion in the transcripts was important, with transcripts read several times to ensure no themes were missed.

Phase 5 - Defining and naming themes

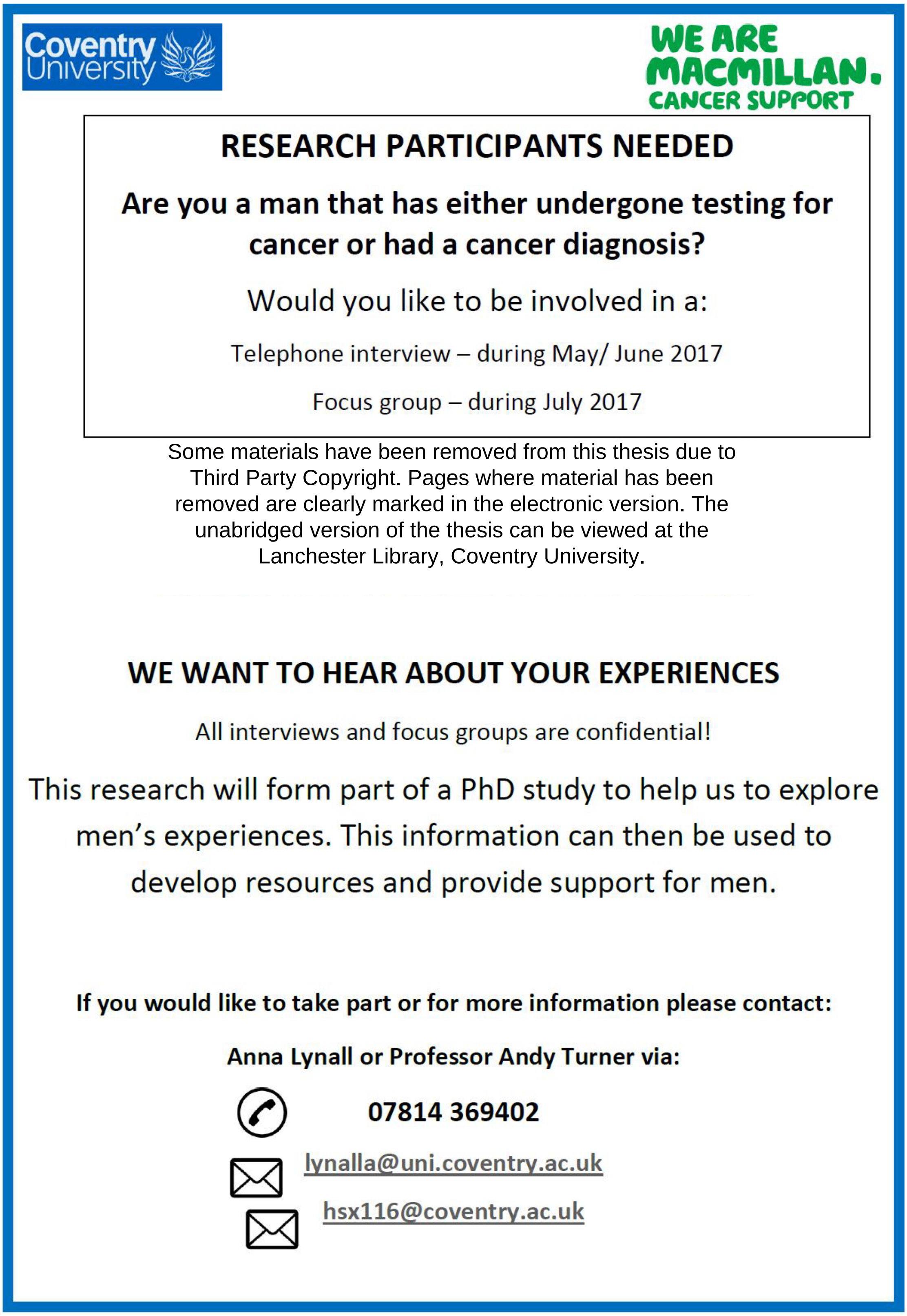
The transcripts were explored further to decipher the name of each theme. Each individual theme was then defined, and evidence from the data was reorganised to ensure all the findings were explicitly clear.

Phase 6. Producing the report

Analysis of the transcripts was carried out to examine the findings and evidence structured by the themes and codes within the framework. The use of quotes illustrated the evidence relating to each theme.

Braun and Clark (2006)

Appendix 7 – Recruitment advertisement poster



Coventry University

WE ARE MACMILLAN. CANCER SUPPORT

RESEARCH PARTICIPANTS NEEDED

Are you a man that has either undergone testing for cancer or had a cancer diagnosis?

Would you like to be involved in a:

Telephone interview – during May/ June 2017

Focus group – during July 2017

Some materials have been removed from this thesis due to Third Party Copyright. Pages where material has been removed are clearly marked in the electronic version. The unabridged version of the thesis can be viewed at the Lanchester Library, Coventry University.

WE WANT TO HEAR ABOUT YOUR EXPERIENCES

All interviews and focus groups are confidential!

This research will form part of a PhD study to help us to explore men’s experiences. This information can then be used to develop resources and provide support for men.

If you would like to take part or for more information please contact:

Anna Lynall or Professor Andy Turner via:

☎ **07814 369402**

✉ lynalla@uni.coventry.ac.uk

✉ hsx116@coventry.ac.uk

Appendix 8 – Participant Information Sheet for Interviews

Information Sheet for Participants
Version 1.1 (14/02/2017)

Study Title: Exploring the needs of men during the early detection of cancer.

We would like to invite you to take part in a research study. Before you give your consent to participate in the research it is important that you understand why the research is being conducted and what you will be asked to do.
Please take time to read the following information sheet and discuss it with others if you wish. **You are under no obligation to participate in the study and it is entirely up to you whether you decide to take part in the study or not.**

What is the purpose of the study?
The purpose of the study is to gain an understanding of how men feel during the waiting period before a diagnosis of cancer or whilst undergoing surveillance for cancer. The aim of the project is to explore what needs men have during the early detection stage of cancer. The study also aims to explore men's wellbeing and quality of life during the pre-diagnosis stage. We hope that the information we gain will help us to use this information to develop resources and provide support for men in this early detection stage.

Why have I been chosen?
You have been contacted as you have either undergone testing for cancer or have had a cancer diagnosis and currently attend a support group.

What are you asking of me?
We would like you to take part in a telephone interview to discuss your experience of the early detection period. Interviews will last approximately 45 minutes. The interviews will be audio taped for the purpose of producing a verbatim (word-for-word) transcript. All information provided will be anonymised and kept confidential so your responses will be unidentifiable.

Who will have access to the recording and transcript of the interview?
Only the researcher (Anna Lynall) will have access to the recording. The sound file will be stored on a password protected computer at Coventry University and deleted in January 2019. The researcher, supervisors and assessors will have access to fully transcribed anonymised interviews. The transcripts will be stored in a locked filing cabinet at the Coventry University and only the study researchers will have access to this information.

How will you protect my anonymity and that of other people I might mention?
You will be asked to pick a pseudonym (a false name) for yourself and any patients, colleagues or significant others (e.g. friends) that you mention during the interview. This means that your identity will remain fully anonymous. Only the researcher will know your identity.

Will my taking part in this study be kept confidential?
Yes. This study will comply with the Data Protection Act 1998 and your participation will be kept confidential.

Only members of the research team will have access to the data. All the consent forms will be stored in a separate, secure (locked) location from the data itself. You will only be identified by your pseudonym. Any data which may identify you will be locked in a secure filing cabinet and no identifiable information will be included in any report or publication relating to this study.

What are the possible disadvantages and risks of taking part?

We are not aware of any risks to you in taking part. We are however aware that there is the possibility that some people may feel upset discussing cancer. However, we will provide you with a useful contact number for Macmillan Cancer Support, an organisation you can speak to if you require further support (see contact details).

What if something goes wrong?

If you change your mind about taking part in the programme you can withdraw at any point. You can email, telephone or write to me (see Anna Lynalls contact details). If you have a concern about any aspect of this research, please speak to the researchers at Coventry University who will do their best to answer your questions (See Anna Lynall's contact details). You can also contact Professor Andrew Turner (see contact details). Coventry University has comprehensive public liability insurance to cover negligent harm. Coventry University's insurers do not automatically provide non-negligent indemnity cover. In those circumstances where non-negligent cover is advised or is essential, cover will be sought on a case to case basis.

What will happen to the results of the study?

The anonymised input to the research will be used for research purposes (publications and conferences) and will inform future research, and the development of resources, to provide support for men in the early detection stage of cancer.

What happens if I have any further questions or concerns?

If you have any further questions or concerns about your participation in this research you can contact Anna Lynall by telephone 07814 369402 or email lynalla@uni.coventry.ac.uk. You can also contact Professor Andrew Turner by email hsx116@coventry.ac.uk or by post at 4th Floor, Richard Crossman Building, Centre for Technology Enabled Health Research (CTEHR), Faculty of Health & Life Sciences, Coventry University, Priory Street, CV1 5FB.

Who is involved in this study?

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For Support
Macmillan Cancer Support
0808 808 00 00
http://www.macmillan.org.uk

Appendix 9 – Participant Consent Form for Interviews

Study Title: Exploring the needs of men during the early detection of cancer.

Consent Form for Participants
Version 1.1 (14/02/2017)

Please tick each statement to indicate agreement:

☐ I have read and understood the information sheet for the above study (Version 1.1 dated 14/02/2017) and have been given the opportunity to ask questions.

☐ I understand that my participation is voluntary and that I am free to withdraw from the study without having to give any reason and without me being affected or this having any negative consequences on my circumstances.

☐ I agree to provide information that will be used for research purposes only. I understand that all the information relating to myself obtained as part of the study will be strictly confidential, and that I will not be personally identified in any write-up of the results. I understand my name and any personal details will be anonymised.

☐ I understand that information will be stored in secured manual and electronic files and is subject to the provisions of the Data Protection Act.

☐ I understand that I am being asked to participate in an interview (approximately 45 minutes in duration) and discuss a series of points relevant to the study. I understand that the whole interview will be recorded.

☐ I wish to participate in this study under the conditions set out here and in the Information Sheet for Participants.

______________________	________________	_______________
Print Name of Participant	Date	Signature
________________________	_________________	________________
Researcher	Date	Signature

Appendix 10 – Interview questions

Interview Schedule
Version 1.1 (24th April 2017)

Age	
Marital Status	
Ethnicity	
Date of testing	
Type of testing	
Support Group affiliation	

Information for participant:
The purpose of the study is to gain an understanding of how men feel during the waiting period before a diagnosis of cancer or whilst undergoing surveillance for cancer. The aim of the project is to explore what needs men have during the early detection stage of cancer. The study also aims to explore men's wellbeing and quality of life during the pre-diagnosis stage. We hope that the information we gain will help us to use this information to develop resources and provide support for men in this early detection stage.

Has participant sent back consent form: Yes/ No

Has participant read info sheet: Yes/ No

1. **Can you tell me about the waiting period between having screening (or a test) and then receiving the results of the test?**

2. **How long did you have to wait (to get the results of the test)?**

- How did you feel during the time leading up to getting your test results?

- What were you thinking during the time leading up to getting your test results?

- Did you seek any support during this period of time (and from what sources – informal/formal)? **If no,** what sources of support would you have liked if any?

- Did you seek any information (and from what sources – informal/ formal)? **If no,** what sources of information would you have liked if any?

3. **Can you tell me about when you were given the test results?**

- What were your expectations?

- What were your immediate thoughts after the results were given?
- What were your immediate feelings after the results were given?

4. **How were the test results communicated to you?**

- Were you satisfied with the way the results were communicated to you?

  If yes, can you explain why?

  If not, what would have been more acceptable?

5. **Was your wellbeing ever discussed with you, either during the waiting period or upon receiving your test results?**

If yes or no, how did or how would you feel about that? **Prompt: emotionally/psychologically**

6. **When did you feel you required the most support throughout your experience?**

7. **Thinking back to that period of time (between having the test and receiving the result) is there anything additional that would have helped or that you would have found useful?**

Finally: Is there anything you would like to add that you feel we have not covered?

Mention opportunity to be part of developing a prototype:

Happy to be involved: Yes/ No

Appendix 11 – Participant Information Sheet for Consensus Workshop

Information Sheet for Participants
Version 1.1 (14/02/2017)

Study Title: Exploring the needs of men during the early detection of cancer.

We would like to invite you to take part in a research study. Before you give your consent to participate in the research it is important that you understand why the research is being conducted and what you will be asked to do.

Please take time to read the following information sheet and discuss it with others if you wish. **You are under no obligation to participate in the study and it is entirely up to you whether you decide to take part in the study or not.**

What is the purpose of the study?

The purpose of the study is to gain an understanding of how men feel during the waiting period before a diagnosis of cancer or whilst undergoing surveillance for cancer. The aim of the project is to explore what needs men have during the early detection stage of cancer. The study also aims to explore men’s wellbeing and quality of life during the pre-diagnosis stage. We hope that the information we gain will help us to use this information to develop resources and provide support for men in this early detection stage.

Why have I been chosen?

You have been contacted as you have either undergone testing for cancer or have had a cancer diagnosis.

What are you asking of me?

We would like you to take part in a focus group to discuss your experience of the early detection period. The focus group will last approximately 1 hour. The focus group will be audio taped for the purpose of producing a verbatim (word-for-word) transcript. All information provided will be anonymised and kept confidential so your responses will be unidentifiable.

Who will have access to the recording and transcript of the interview?

Only the researcher (Anna Lynall) will have access to the recording. The sound file will be stored on a password protected computer at Coventry University and deleted in January 2019. The researcher, supervisors and assessors will have access to fully transcribed anonymised focus group scripts. The transcripts will be stored in a locked filing cabinet at the Coventry University and only the study researchers will have access to this information.

How will you protect my anonymity and that of other people I might mention?

You will be given a participant code number. This means that your identity will remain fully anonymous. Only the researcher will know your identity.

Will my taking part in this study be kept confidential?

Yes. This study will comply with the Data Protection Act 1998 and your participation will be kept confidential.

Only members of the research team will have access to the data. All the consent forms will be stored in a separate, secure (locked) location from the data itself. You will only be identified by your participant code number. Any data which may identify you will be locked in a secure filing cabinet and no identifiable information will be included in any report or publication relating to this study.

What are the possible disadvantages and risks of taking part?
We are not aware of any risks to you in taking part. We are however aware that there is the possibility that some people may feel upset discussing cancer. However, we will provide you with a useful contact number for Macmillan Cancer Support, an organisation you can speak to if you require further support (see contact details).

What if something goes wrong?
If you change your mind about taking part in the programme you can withdraw at any point. You can email, telephone or write to me (see Anna Lynall's contact details). If you have a concern about any aspect of this research, please speak to the researchers at Coventry University who will do their best to answer your questions (See Anna Lynall's contact details). You can also contact Professor Andrew Turner (see contact details). Coventry University has comprehensive public liability insurance to cover negligent harm. Coventry University's insurers do not automatically provide non-negligent indemnity cover. In those circumstances where non-negligent cover is advised or is essential, cover will be sought on a case to case basis.

What will happen to the results of the study?
The anonymised input to the research will be used for research purposes (publications and conferences) and will inform future research, and the development of resources, to provide support for men in the early detection stage of cancer.

What happens if I have any further questions or concerns?
If you have any further questions or concerns about your participation in this research you can contact Anna Lynall by telephone 07814 369402 or email lynalla@uni.coventry.ac.uk. You can also contact Professor Andrew Turner by email hsx116@coventry.ac.uk or by post at 4th Floor, Richard Crossman Building, Centre for Technology Enabled Health Research (CTEHR), Faculty of Health & Life Sciences, Coventry University, Priory Street, CV1 5FB.

Who is involved in this study?

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0808 808 00 00
http://www.macmillan.org.uk

Appendix 12 – Consent form for consensus workshop

Study Title: Exploring the needs of men during the early detection of c

Consent Form for Participants
Version 1.1 (14/02/2017)

Please tick each statement to indicate agreement:

☐ I have read and understood the information sheet for the above study (Version 1.1 dated 14/02/2017) and have been given the opportunity to ask questions.

☐ I understand that my participation is voluntary and that I am free to withdraw from the study without having to give any reason and without me being affected or this having any negative consequences on my circumstances.

☐ I agree to provide information that will be used for research purposes only. I understand that all the information relating to myself obtained as part of the study will be strictly confidential, and that I will not be personally identified in any write-up of the results. I understand my name and any personal details will be anonymised.

☐ I understand that information will be stored in secured manual and electronic files and is subject to the provisions of the Data Protection Act.

☐ I understand that I am being asked to participate in a focus group (approximately 1 hour in duration) and discuss a series of points relevant to the study. I understand that the focus group will be recorded.

☐ I wish to participate in this study under the conditions set out here and in the Information Sheet for Participants.

______________________	__________________	_________________
Print Name of Participant	Date	Signature
________________________	___________________	__________________
Researcher	Date	Signature

Appendix 13 – Modified version of NGT Protocol

Potter et al, (2004) NGT protocol:

1.Introduction and explanation
2. Silent generation of ideas
3. Sharing ideas
4. group discussion
5. Voting and ranking

The modified version described below omitted Step 2 – The silent generation of ideas

The NGT modified version used:

1. **Introduction and explanation**: Participants were welcomed, and the purpose and procedure of the meeting was explained by the researcher (duration - 20 minutes).

2. **Presentation of ideas**: each participant was presented with a short booklet with the generated needs outlined. The identified needs were also on a flipchart next to the table where participants were sitting. Consideration of issues related to literacy levels or visual impairment were taken into account and mitigated by the researcher reading out loud the booklet and allowing time for any questions or clarification (duration - 30 minutes).

3. **Group discussion**: Participants were invited to seek verbal explanation or further details about any of the needs that were produced that may not be clear to them. The researcher's task was to ensure that each person could contribute, by allowing ample time for contributions and using eye contact to encourage contributions, and that discussion of all the needs was thorough without spending too long on a single factor. The facilitator reiterated that every contribution was valuable as it was important to ensure that the process was as neutral as possible to avoid judgment or criticism. The group had opportunity to suggest new items about their needs for discussion, but no needs were eliminated (duration - 30 minutes).

4. **Voting and ranking**: This involved prioritising the recorded needs in relation to the original question. Each participant was given a sheet of number coloured dots and individually ranked the identified needs in priority order, starting with 1 as the highest priority and 2 as the second and so on. Participants could visually see the immediate results in response to the question, and the meeting concluded having reached a specific outcome (duration - 30 minutes).

   Duration: the NGT workshop lasted for 110 minutes in total.

Appendix 14 – Participants Identified needs

1. Accessibility and acceptability of their social support network
2. Having at least one ‘supportive individual’ to talk to
3. Perceived control to plan and prepare
4. Risk perception communicated by Healthcare professionals and trusted peers (Plain English/ lay man’s terms is appreciated)
5. Having an ‘outlet’ for releasing anxiety and worry
6. Gaining knowledge through credible information sources
7. Ability to plan and prepare for next steps and the future (much wider than health)
8. Gaining control through increased knowledge
9. Effective, honest and open communication from Healthcare Professionals (upfront and to the point) with compassion
10. Preparatory information seeking (supports the next stage)
11. To have a distraction such as work (paid or voluntary) or meaningful activities
12. To ‘compartmentalise’ the anxiety and deal with it in stages
13. To not ‘burden’ others
14. The use of humour to lighten communications
15. The value of peer support (and the lived experiences of others who had experience of cancer)
16. Dealing with anxiety, shock and disbelief
17. Issues of masculinity, stoicism, cultural expectations
18. Gender of Healthcare professionals involved in care
19. The role of HCPs and trusted peers in instilling hope and confidence
20. Importance of individuality and person centred support
21. Internet use for knowledge and information gathering
22. Dealing with uncertainty
23. Psychosomatic impact on physical health
24. Confidence and support to self manage (willing to self manage but having the confidence to know what is ‘right’)
25. Timing of support

Appendix 15 – Participants Identified needs with excerpts from the transcripts

Need identified	Examples
Accessibility and acceptability of their social support network	(P20) I talked about my brothers problem and he talked to me about mine and I talked to Stephen(*) about it and that was all. I told my in-Laws about it,[..] we've got some friends that we've known for forty odd years and I told them 'cause they said "right what's happened and I explained..." P10) from reading and from friends I'd had that had the same experience and being the sort of person I am, I got on with it. […] I didn't particularly look for support but I suspect actually I was getting a lot from friends who'd gone through or were going through the experience. And doing through that, quite a lot about it produces relaxation if you understand what's happening and why it's bound to help.
Having at least one 'supportive individual' to talk to	(P15) You know, my wife, she was keeping checks on the letters she was making the phone calls, she was driving me there. She was a rock, you know, in that respect. But that's how she is... (P25) […] I think Nola (daughter) sort of, she knew what to say she knew the right things to say and how to make me feel that I was going to get sorted. That's how I felt. So Sheila (wife) was very supportive aswell. So she was positive, madly positive. It isn't the same for everyone, she's not an optimist as I am but she stayed very sort of positive…
The value of peer support (and the lived experiences of others who had experience of cancer)	(P4)[…] I just talked to people I knew, you know, colleagues, ex-colleagues of a similar age or friends and found a couple of those that had been or were going through the same process so it was just interesting to sort of share notes with them. (P24) […] two of my friends have both had the operation, one will be 12 months last September and the other one had his in April and they've been very good talking to me about the process so that's been really useful.
Perceived control to plan and prepare	(P1) … the other thing that was important, I don't take time off, working it's that kind of stuff… so after I had a biopsy I went straight to a conference to deliver a session […] all of that stuff was around just trying to keep going and not think about it and then the emotions would spill over in terms of just thinking…oh….bloody hell if this is something I have I've got to manage that, what's the impact going to be […]….if it is something more serious how am I going to manage all of that […] at that point I would want to be talking to someone just to think about…if that is what it's going to be, how am I going to be planning, what are the things that are important around finances, job, how am I going to manage those things… I would want to do some of that thinking, in that moment rather than waiting to be told, yes you have this, I'd rather already begin some of that thinking. (P6) the uncertainty of when will I get a letter from the hospital, when will the appointment be, and not being in charge of my own life like. Can I book a holiday? When can I get back to my normal pace? […] That was out of my hands and I didn't like that so I changed that. The delay and not having information about it causes more people anxiety than anything else I think.
Having an 'outlet' for releasing anxiety and worry	(P5)…there are moments where you get, you start to well up a little bit and you know, so me times, when I'm thinking about things in the car on the way back from site visits and things like that you know its difficult to, I find it difficult to…person to show feelings aswell really so I think it gets bottled up a little bit and I think some of those were feelings were when I was getting this bad tension in my back and things like that you know.

To have a distraction such as work (paid or voluntary) or events	(P5) I've been lucky actually in the fact that I've carried on working because I wasn't quite sure what I was gonna do. What the timescale was. So I was in at work most of the time so, yeah, I wasn't over troubling myself and I was, as far as my job is concerned, I'm guess I've learnt to live with things and wait until you get the result. (P11) I'd got a full time job and a family so not a lot of time to sit around and twiddle your thumbs and worry. […] …. I'd have been annoyed at the prospect of having time off work in both cases and having to go into hospital.
To 'compartmentalise' the anxiety and deal with it in stages	(P5) personally I can put it on the back of my mind and think right, in a couple of weeks I'm gonna get that result but, you know, I don't sort of dwell on it too much really so I think it was quite good. (P20) I didn't worry too much, it was only occasionally, to repeat myself, but, that I would get, I thought, well I've got this growth, its cancerous and they're going to do something about it and then I'd put it to the back of my mind really.
Ability to plan and prepare for next steps and the future (much wider than health)	(P5)[…] my feelings were directed towards practically what would I do if I got this sort of situation and I guess that practically, issues at work, you know, do I retire quickly and things like that really. (P15) I wasn't really listening. When they, when the Doctor said, you know it's what it was, they said, they said obviously they'd remove the testicle so, I had the biopsy and then they said, right its cancer, its Non Hodgkinson's, […]… And then you just, you're thinking of the dates you're not really listening to the medical terms, you think of that's in three weeks' time, what's gonna happen there then. Like my wife was saying, you were trying to work out the fixture list weren't you from football. Trying to work out what games you were gonna possibly miss.
The use of humour to lighten communications	(P9)…there was a gentleman next to me and he'd been waiting for results or something. He'd been sat there waiting for 8 hours in his jeans waiting to go home and we were joking like let's take a nurse hostage and dig a tunnel and …. you know get out. It was very light hearted… (P15) at work like, I would say to the lads, oh I think I've got a lump down below, can you check it for me. Well nobody wanted to check as you can understand but we were making light of it you know.
Dealing with anxiety, shock and disbelief	(P18) Wound up, anxious, depressed. […] It would have been […] about two months. Something like that, part of the biopsy was in November and the diagnosis was in December so about a month and it was a good month or six weeks probably between the doctor(s) referral and actually getting to biopsy. (P7) I was worried. I was apprehensive, worried about results. I was not as positive as I normally was. I'm normally a positive person but I was on a downer obviously if I had cancer then there was, alright I was gonna get treated straight away but if what if it was too advanced to be treated…..
Dealing with uncertainty	P18) Wound up, anxious, depressed. […] It would have been […] about two months. Something like that, part of the biopsy was in November and the diagnosis was in December so about a month and it was a good month or six weeks probably between the doctor(s) referral and actually getting to biopsy. (P7) I was worried. I was apprehensive, worried about results. I was not as positive as I normally was. I'm normally a positive person but I was on a downer obviously if I had cancer then there was, alright I was gonna get treated straight away but if what if it was too advanced to be treated…..

Confidence and support to self manage (willing to self manage but having the confidence to know what is 'right')	(P21) It would have been good if somebody had sat down with me and said, in a quiet room, "are you ok, do you want to have half an hour to just sit? And do you want a cup of tea?" […] even if it was just a Student Nurse or another Nurse just came […] or somebody came and sat me in a room […] take a bit of time, you know. Give yourself that half an hour breathing space. You know, wellbeing type of exercises and things like that. […] it would have been nice to have had some information given me so that I knew what was trustworthy if nothing else. And to have some support, […] just somebody that would just give you some advice, or just direct you to a couple of decent websites and say ignore the others. […] you know somebody to give you good advice if nothing else. Because […] as a civilian and not a medical person I didn't know what was reliable and what was not reliable at the time. (P24) […] They gave me choices and options, call in any time, phone in any time. These are the numbers, these are the people, you've met them,[…] I think I had some marvellous treatment and support but the bottom line is, you've got to do it for yourself. These people are there and make the offer but you've got to take it up. The bus ain't gonna stop and the driver come knocking at your door to tell you the bus is outside is he? At some stage you've got to get out of the chair and walk to the bus stop, and if you don't that's your problem. They've done as much as they can.
Timing of support	(P6) I think I needed the most support at the very beginning. I needed the most support when they did the ultrasound, the Oncology and the X-ray departments …… they took me down to the Oncology Department and that was when I saw the posters up and there was one by a door about Bladder Cancer and I thought obviously they think it's a tumour they think its cancer. (P7) When you've had a sleep on it and you wake up the following morning you think hmmm. Yes. What if its cancer? That was something I thought about and it kept festering inside me, festering, festering, festering and it was probably the Friday when I rang the Support Line.
Psychosomatic impact on physical health	P5) I […] was obviously having an awful lot of tension and that was leading to getting some severe […] back pains. You're almost convinced that something is happening […]I had a bit of time to think and then I had a couple of doubts and I woke up in the night just […] convinced […] that I definitely had got something in my bones, you know and that obviously […] would […] mean a shorter life expectancy […]. You start to think […] what will I do, these sort of things go through your mind. […] that's the sort of thoughts I had….The release when I got the results of that was quite big really. My wife burst into tears and I think I was fairly happy myself! (P16) I had convinced myself that it spread and that every ache and pain I got it just had in that two week period was cancer being there, cancer being in the joints, cancer being in the lungs just that it had spread everywhere. To the point when I had the phone call after the CT Scan I was almost convinced myself where the conversation was gonna go and obviously I was very wrong and for me it wasn't. But that two week period was a long two weeks.
Risk perception communicated by Healthcare professionals and trusted peers (Plain English/ lay mans terms is appreciated)	(P8 […])if he'd have told me in lay man's language, 'cause he was using medical language and I couldn't understand him properly and if he'd have told me more simply in easier words I would probably have understood it more. But he didn't, no. (P21) All sorts were going through my mind. What was interesting and one of the memories I have of that time, almost everybody said, "don't worry about it, it won't be, it can't be cancer you're too young." And that was sort of the Nurses, I'd sort of bumped into, that was sort of the GP as well.

Effective, honest and open communication from Healthcare Professionals (upfront and to the point) with compassion	(P1)…she explained the stuff she was very good she was very sensitive, I really liked her, her style…she was calm and made time in the clinic, the busy clinic actually she made time so I didn't feel like I was being rushed. Yes I was really, I didn't have a problem with that at all, I was really happy with the way she did it. (P18) I went into a small room with a desk with a chap sitting behind it in a white coat, a lady who introduced herself as the Oncology Nurse and some students. That was it really. We sat down, my wife and I and the man said, Mr Winbow(*) you have, what was it, advanced and aggressive cancer. If we cannot, if it has spread outside the prostate we will not be able to cure you but we will help you manage it. Any questions.
The role of HCPs and trusted peers in instilling hope and confidence	(P15)…they said "we're sorry to tell you, you know, but they stress the positives of it, the fact that I had the, if you're gonna get cancer it's the best one to get". You know they didn't paint a doom and gloom picture. (P19) Well I was told by the Surgeon to keep and try and remain very positive about it which I did. And I'm glad I did because I think it's helped me through it. Better than I was expecting to go through it […]it helped me no end to try and keep on top of it.
Gaining knowledge through credible information sources	(P4) I was given the hospital and the constant various literature to read. More about the process of having the biopsy's and all that but that was the written guidance I had and I looked on the Internet myself and looked at things… (P13) I think I was given some literature from Macmillan about prostate cancer and it had how staging works which was very useful. I don't think there was anything that could have been done more really. It was very good.
Gaining control through increased knowledge	(P5) cousin had breast cancer just before, or was diagnosed with breast cancer just before Christmas in about the October so she went in to have an operation and radiotherapy so I have been catching up with her on the odd occasion aswell actually and that's been quite good aswell. So she's been quite good to have a chat to just of a, you know, […] she seems to do quite well aswell you know. All those sort of things have given me, I dunno perhaps too positive a slant on things really. (P6) I want to be in charge of my own calendar If you like. So I said right, I want you make my appointments now like you do at the Dentist. They check if those dates are right. I want you to do the same for me. She said "oh we don't do it like that" (I) said "well there's no reason why you can't is there?" She said "yeah, you're right." And I said "in three months, tell me what the date is and I can check my diary" ….. and she did that. She just asked me for the appointments before she booked them. So now, when I go, I always get there, I'm not sitting at home waiting for a letter to be delivered.
Preparatory information seeking (supports the next stage – buffering?)	(P5) I thought I was, I knows this sounds really strange but I was sort of slightly relieved in some way when I got the first, when I went for the first injection […] there was some indication anyway […] the Nurse had said I think it's a T3B and whatnot and basically I done quite a lot of reading up on the Internet which is a both a good thing and bad thing I think, and I was sort of fairly happy I think for it not be a Stage 4. So to a certain extent if it had been in some ways though it sounds really, really strange it was a relief as I'd spent two or three weeks thinking, wondering how far it got and I really, really don't want it to be a 4 because you look at all the stats don't you and the percentages of survival rates, things like that are significant and your quality of life I guess aswell you know. (P23)…I always felt, through the process, that I was clear about what was happening. They gave me enough information and that I was happy with the path that was taken […] well content. You can't be happy, you've got cancer, but content.

Importance of individuality and person centred support	(P2) Each individual is different. Everyone reacts to any diagnosis differently. How I coped with it is not appropriate to everyone else. It was my unique set of circumstances. A little bit more openness. […] Being open and honest helps you to deal with things a lot better. (P4)…obviously different people would react differently to me it was a question of well I want to know so we can move forward to the next thing if I have to. I didn't go into fits of depression over it or anything. But obviously different people reacted in different ways.
Internet use for knowledge and information gathering	(P2)…I go in still reflecting on this whole thing obviously looked on Google and in my mind I'm already convinced that this is not just routine, they've given this a lot of attention. […] on the notes it says 'suspected SCC' […] I took a copy of that, and obviously when I got home I googled 'SCC' to see what it was. You obviously do self research. In fairness even the CNS said google it, if you want to, you can do it. I think she said it because she knew I had a strong family to support me through it. (P6) when I got home from the Ultrasound and they said there was a tumour, I then went and looked it up on the Internet and various things.
To not 'burden' others and selective disclosure	(P1) I didn't want to tell her I was worried or anything…..I just wanted to manage in terms of myself […] I don't know why I did that but there was just something…. I don't know…being a hero, I don't know what it was, just…you know… doing it on your own….and maybe again being single and not having kids or a wife or a partner (because I am gay) ..but not having a partner…actually it feels…as a single person sometimes if you get unwell and you're worried about something…you don't want to burden other people with it […] I think its different when its your partner, I don't know maybe you can share that load… not wanting to talk about it and that's probably not a great thing? Probably not a great thing […] But the question is who would I speak to, without? You don't want to turn it into a drama…. (P12) …I don't know how I got through that time to be honest. My sons couldn't help because, I've got two sons and they just, they've got their own lives so I had to face up to the fact that I had cancer, that I somehow had to get through the two weeks that I had between the diagnosis and the surgery.
Gender of Healthcare professionals involved in care	(P6)…one of the things that set me back, that was the way I was told about my condition. I'm sure if I was a women and I was to be given that information, I think it would have been done differently. I think from a perspective of Doctors and Consultants like you know, when they inform men about something like that they do it differently. They do it in a macho style you know what I mean rather than the gentle approach. Its true. Most men aren't likely to burst into tears. Its not macho to do that, and I think Doctors, especially men giving men that kind of news to other men then trying to be like, you know, the macho type approach, like a man may approach you, you know what I mean? Rather than the sensitive approach.

Appendix 16 – Evaluation questionnaire for digital stories

Evaluation form for Participants
Version 1.1 (01/01/2018)

Evaluating the experience of being involved in the early detection digital story workshop

1. What were your reasons for deciding to participate and make a digital story about your experiences of the early detection period?

2. What did you like most about the experience?

3. Did you gain anything from the experience?

4. Was there any part of the session that you found difficult?

5. Overall, what did you think about the experience of being involved with the workshop?

6. What could have made the experience better?

7. When you watched your digital story back were you pleased with it? Why or why not?

8. There was a researcher and camera man in the room with you, what was it like working with them?

9. Do you think making films about men's experiences is a good way to tell the community about personal experiences during the early detection period? Why or why not?

10. How would you like to see your digital story being used to tell others about coping during the early detection period?

11. How did talking about your experience during the workshop compare with the phone interview you took part in?

12. Please write down here anything else you would like us to know about the experience of being involved.

Appendix 17 – Participant Information Sheet for digital stories

Information Sheet for Participants
Version 1.1 (01/01/2018)

Study Title: Exploring the needs of men during the early detection of cancer.

We would like to invite you to take part in a research study. Before you give your consent to participate in the research it is important that you understand why the research is being conducted and what you will be asked to do.

Please take time to read the following information sheet and discuss it with others if you wish. **You are under no obligation to participate in the study and it is entirely up to you whether you decide to take part in the study or not.**

What is the purpose of the study?

The purpose of the study is to develop an intervention that will support men during the waiting period before a diagnosis of cancer or whilst undergoing surveillance for cancer. The aim of the project is to explore what needs men have during the early detection stage of cancer. The study aims to explore men's wellbeing and quality of life during the pre-diagnosis stage. We hope that the information we gain from what men tell us about their experiences will help us develop resources and provide support for men in this early detection stage.

Why have I been chosen?

You have been contacted as you have either undergone testing for cancer or have had a cancer diagnosis and currently attend a support group.

What are you asking of me?

We would like you to take part in a face to face short interview to discuss your experience of the early detection period. Interviews will last approximately 45 minutes. The interviews will be filmed for the purpose of producing a number of film clips that can be used in an online intervention to support men going through this early detection stage. The clips will be used to illustrate the experiences of other men going through testing and waiting for the results.

What are the possible disadvantages and risks of taking part?

We are not aware of any risks to you in taking part. We are however aware that there is the possibility that some people may feel upset discussing cancer. However, we will provide you with a useful contact number for Macmillan Cancer Support, an organisation you can speak to if you require further support (see contact details).

What if something goes wrong?

If you change your mind about taking part in the programme you can withdraw within the timescales of the study (up until January 2019). You can email, telephone or write to me (see Anna Lynalls contact details). If you have a concern about any aspect of this research, please speak to the researchers at Coventry University who will do their best to answer your questions (See Anna Lynall's contact details). You can also contact Professor Andrew Turner (see contact details). Coventry University has comprehensive public liability insurance to cover negligent harm. Coventry University's insurers do not automatically provide non-negligent indemnity cover. In those circumstances where non-negligent cover is advised or is essential, cover will be sought on a case to case basis.

What will happen to the results of the study?
The input to the research (the film of you describing your experiences) will be used for research purposes (publications and conferences) and will inform future research, and the development of resources, to provide support for men in the early detection stage of cancer.

What happens if I have any further questions or concerns?
If you have any further questions or concerns about your participation in this research you can contact Anna Lynall by telephone 07814 369402 or email lynalla@uni.coventry.ac.uk. You can also contact Professor Andrew Turner by email hsx116@coventry.ac.uk or by post at 4th Floor, Richard Crossman Building, Centre for Technology Enabled Health Research (CTEHR), Faculty of Health & Life Sciences, Coventry University, Priory Street, CV1 5FB.

Who is involved in this study?

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For Support
Macmillan Cancer Support
0808 808 00 00
http://www.macmillan.org.uk

Appendix 18 – Participant Consent Form for digital stories

Study Title: Exploring the needs of men during the early detection of c

Consent Form for Participants
Version 1.1 (01/01/2018)

Please tick each statement to indicate agreement:

☐ I have read and understood the information sheet for the above study (Version 1.1 dated 01/01/2018) and have been given the opportunity to ask questions.

☐ I understand that my participation is voluntary and that I am free to withdraw from the study without having to give any reason and without me being affected or this having any negative consequences on my circumstances.
☐ I agree to provide information that will be used for research purposes only.

☐ I understand that I am being asked to participate in an interview (approximately 45 minutes in duration) and discuss a series of points relevant to the study. I understand that the interview will be filmed.

☐ I wish to participate in this study under the conditions set out here and in the Information Sheet for Participants.

I, the undersigned, consent to the use of my words, images, images of my work or recordings of my voice being used within Coventry University publications or video case studies. I understand that this may be used for educational, marketing, and/or commercial purposes, and that copyright will reside with Coventry University.

I acknowledge that the quote, image or recording may also be used in, and distributed by, media pertaining to Coventry University's activities other than a printed publication, such as, but not limited to CD-ROM, DVD or the World Wide Web.

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Print Name of Participant	Date	Signature
Researcher	Date	Signature

Please complete the Participant details below and return the form to Anna Lynall, PhD Student, the University contact;

Participant's details:

I require/do not require that
my name is removed/retained
in association with images and/or recordings
(please delete as appropriate)

Coventry University Contact:
Name: Mrs Anna Lynall/ Professor Andy Turner
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