

ABSTRACT

Prostate cancer impacts on the daily lives of men, particularly their physical and emotional health, relationships and social life. This paper highlights how men cope with disease and treatment and the strategies they employ to manage their diagnosis alongside daily life. Twenty seven men were interviewed prior to radiotherapy and 6-8 and 12-18 months post radiotherapy, to explore how they managed their disease at different stages of their treatment pathway. A grounded theory approach was used to collect and analyse the data. Five main themes emerged: pathway to diagnosis; interpretation of the diagnosis; making sense of cancer in daily life; managing the impact of treatment and living with prostate cancer in the long-term. Prostate cancer was diagnosed using the PSA test, rectal examination and biopsy. Many men did not understand the consequences of a high PSA reading before they undertook the test. Painful investigative biopsies being viewed as the worst part of the disease experience. Radiotherapy was considered less invasive compared to other treatments, however preparatory regimes were often associated with stress and inconvenience. Men used various strategies to accommodate prostate cancer in the long-term, particularly when masculine identity was challenged as a result of bodily changes arising from treatment.

Keywords: prostate cancer; radiotherapy; qualitative research; masculinity; experiences

BACKGROUND

Prostate cancer is a significant cause of morbidity and mortality in men, especially in those over the age of 75 years. It is the most commonly diagnosed cancer in men in the UK, accounting for almost 1 in 4 of all new male cancers diagnosed (Wilt and Thompson, 2006; Cancer Research UK, 2013). Nearly 42,000 new cases were diagnosed in the United Kingdom in 2010 (Cancer Research UK, 2013), as compared with over 35,500 in 2004 (Westlake & Cooper, 2009). More than 10,000 men die annually from the disease (Kelsey et al, 2004; DH, 2006; Cancer Research UK, 2013).

Improvements in detection methods and an increase in survival rates has inevitably resulted in more patients being treated for and living with prostate cancer, resulting in a significant impact on health service provision. Since the introduction of the NHS Cancer Plan in 2000 (DH, 2000), there have been various initiatives to improve prostate cancer services in the UK (NHS Executive, 2000; NICE, 2002; NICE, 2008; Burford et al, 2010; DH, 2011). However, there is no population based national screening programme for prostate cancer in the UK and there is considerable debate regarding the reliability of Prostate Specific Antigen (PSA) test. In the absence of a screening programme, the current focus is to “give clear and balanced information to asymptomatic men who ask about testing for prostate cancer” (Burford et al, 2009). A call for clear information is welcomed given that earlier studies have indicated that men felt under-informed prior to undergoing PSA testing (Chapple et al, 2002; Slevin et al, 1999; Dube et al, 2005) and is especially significant when one considers that an elevated PSA is considered a turning point for men (Kazer et al, 2011).

The optimal treatment for prostate cancer is not known (Lin et al, 2009). Decisions regarding treatment modality are dependent upon the grade (histological grade/Gleason score), stage and PSA result; and take into account life expectancy, co-morbidities, quality of life and patient preference (NICE, 2008; Wilt and Thompson, 2006). Patients with localised or locally advanced prostate cancer have treatment options which include: active surveillance, watchful waiting, radical prostatectomy, radiotherapy (external beam radiotherapy (EBRT) and/or brachytherapy) or hormone therapy (NICE, 2012; Prostate Cancer UK, 2013a). Latest figures from NICE indicate that 26% of men receive radical radiotherapy (most commonly EBRT) and the majority of these receive hormone therapy in combination (NICE, 2013). EBRT in combination with hormone therapy improves survival when compared to EBRT alone, but this is associated with increased adverse effects during and following treatment (Ihrig, 2011; Sanda et al, 2008). EBRT involves daily visits to a radiotherapy centre over a number of weeks. Patients often experience distressing physical side effects which include: urinary incontinence, bowel dysfunction, fatigue, impotence and infertility (Prostate Cancer UK, 2012). Hormone therapy reduces the level of testosterone in the body and may cause impotence, hot flushes, sweating, gynaecomastia, weight gain, cognitive impairment, mood swings, depression and

bone thinning (Grunfield et al, 2012; Prostate Cancer UK, 2013b). A major concern to patients is treatment side effects, and evidence suggests that the advice given by the consultant and the experience of other patients has a significant influence on decision-making (Ihrig, 2012; Sinfield et al, 2009)

Quality of life (QoL) measures have often been used to evaluate the impact of treatment on men's health and well-being (Penson et al, 2003). A quantitative longitudinal study found that radiotherapy had a deleterious effect on global QoL (McCaughan et al, 2013). The study of 149 men demonstrated that QoL for all participating men declined in the first four to six weeks of treatment. There were improvements at the six and twelve months time points, yet a minority of men reported experiencing severe urinary and bowel symptoms one year post radiotherapy treatment. However, it should be noted that these men began the study with more severe symptoms pre-treatment. It is clear that men experience variations in QoL over time and those experiences are shaped by the type of treatment they receive. A US study by Sanda et al. (2008) measured QoL amongst men before and after radical prostatectomy, brachytherapy and external-beam radiotherapy. They found that treatment-related QoL was significantly associated with satisfaction levels amongst men and their spouses/partners, with distressing symptoms leading to reduced satisfaction. The authors acknowledged that lack of sample randomisation prohibited the comparison of treatment outcomes and the study did not extend beyond two years when further QoL changes could be expected. However, men's experiences of prostate cancer have not only been assessed using quality of life instruments, but have been subject to a gendered discourse in which their health has been viewed as a consequence of socio-cultural-political influences.

Barriers to understanding men's health experiences have traditionally involved a paucity of evidence, narrow and inappropriate definitions of men's health and assumptions concerning the relationship between their behaviour and health outcomes (Robertson, 2006). The literature describes how men's health behaviour is shaped by the traditional dominant socio-cultural script of hegemonic masculinity, but emphasises how individuals adopt other forms of masculinity and negotiate deviations from social norms to fit the situation (O'Brien et al, 2005; McVittie and Willock,

2006). Research evidence suggests men often feel unable to discuss how they feel and delay seeking help as they strive to maintain the traditional stoic, fearless image (Chapple and Ziebland, 2002; Sabo, 1999; Courtenay, 2000). Institutional and social structures further reinforce and undermine men's attempts to adopt healthier habits (McVittie and Willock, 2006; Sabo, 1999) through lack of gender aware policies that promote men's early presentation to health services. Furthermore, men's inclination to avoid health services has been linked to poor understanding of how men negotiate their health, ill-health and its relationship to masculine identity. According to Kelly (2009) more research is required into how men deal with the physical and emotional vulnerability associated with prostate cancer. He suggests that men reclaim their former selves through coping strategies that make prostate cancer less threatening, such as emphasising physical fitness and adjusting to a 'new' body that defies conventional masculinity.

It is important to understand the lived experiences of men with prostate cancer and the impact of their gender on their experience of the disease and its treatment. Whilst the body of research surrounding prostate cancer is increasing, research into men's experiences of prostate cancer whilst receiving radiotherapy treatment is more limited (Tarnhuvud et al, 2007). Radiotherapy is a key treatment choice often administered alongside hormone therapy, yet there are limited qualitative studies which explore men's experience of living with prostate cancer whilst undergoing radiotherapy treatment. While the focus of policy recommendations has generally been to encourage person-centred care and treatment through a multi-disciplinary approach (NHS Improving Quality, 2013) there is a relatively low underpinning evidence base detailing the patient experience of receiving treatment for prostate cancer.

It should be noted that men may not associate treatment side effects (e.g. urinary and bowel dysfunction) with diminished quality of life, as they may not view such dysfunctions as aspects of health but as inevitable consequences of treatment or old age (Korfage et al, 2006; McPherson et al, 2001). In an interesting Swedish study by Lindqvist et al. (2006) the meanings that men with prostate cancer attributed to their disease and bodily symptoms were explored using a phenomenological approach. This was a cross-sectional study involving men with metastatic disease, Wellbeing

and QoL were viewed as cyclical processes, where periods of illness and wellness were accommodated using personal resources and coping mechanisms. There is very little research which explores the experience of men at different stages of curative treatment for prostate cancer. This study was designed to explore this under-researched area and will highlight the way in which men manage their disease and treatment in their everyday lives.

METHODS

DESIGN

A cross-sectional qualitative design using semi-structured, face-to-face interviews and a constructivist grounded theory approach (Charmaz, 2006) was adopted. The grounded theory approach assumes that social reality is individually constructed and recognises the mutual creation of knowledge between the researcher and research participant, suggesting that an interrelationship exists between them (Charmaz, 2003; Mills et al, 2006). The method assumes that the themes and theories generated from the data are constructed through the experiences, interactions and meanings attributed by the researcher and research participant. Hence, reality is grounded in the interpretation of events or occurrences and is dependent on the views and values held by the individual.

EHTICAL CONSIDERATIONS

The study was approved by an NHS Research Ethics Committee and the participating cancer centre. Informed written consent was obtained from participants. All data were anonymised and participants' identity protected through the use of pseudonyms.

SAMPLE

Patients attending the outpatient clinic were offered a Study Information Pack by a member of their clinical team, containing a letter of invitation to participate in the study, an information sheet and a reply slip and prepaid envelope. Patients who were

interested in participating in the study were asked to send their contact details via the reply slip to the research team who contacted them to discuss the study and respond to any questions. A purposive sample of twenty seven participants was recruited at different stages: prior to curative external beam radiotherapy (EBRT) and 6-8 months and 12-18 months following completion of EBRT. This cross-sectional study aimed to capture and understand the experiences of men with prostate cancer at different time-points. The time-points were chosen for pragmatic reasons and were based on the literature, but permitted the exploration of whether these time-points were important. The participant was invited to take part in one recorded interview with the researcher at a location of their choice.

DATA COLLECTION

A topic guide was developed based on existing literature and feedback from men attending a local prostate support group who had agreed to participate in a pilot study. Topics included the impact of the disease and treatment on their physical and emotional health, family and personal relationships, social and occupational roles. Interviews lasted between 30 and 120 minutes and were transcribed verbatim. Data collection and analysis proceeded in tandem with each stage informing the other.

DATA ANALYSIS

The transcripts were initially read and re-read and coded line-by-line using a descriptive label to reflect the data segment. As coding and data collection progressed simultaneously, codes were organised into higher level categories which enabled greater explanatory potential. Through a process of constant comparison, data were used to expand pre-existing categories and generate new categories as similarities and differences were identified. Similar concepts were grouped together and patterns established which helped to explain the development of the core categories. Theoretical saturation was reached when no new themes emerged from the analysis process that was significant to the emerging theory. Data analysis was managed by the research team at an individual and group level. Each individual researcher analysed their own interviews and then discussed their responses within the group. Data

frameworks and matrices were developed to standardise the process and to ensure that results were consistent and reflected the data. The research team also used reflective diaries to make their interpretation and understanding of the narrative text explicit and transparent.

FINDINGS

Five main themes emerged from the analysis of the data: pathway to diagnosis; interpretation of the diagnosis; making sense of cancer in daily life; managing the impact of treatment and living with prostate cancer in the long-term. These five themes reflected the time-points that were significant to the experiences of men, with each theme containing a unique set of events which impacted on the overall disease experience. The pathway to diagnosis was noted for its investigational and diagnostic procedures and the physical and emotional effects of undergoing painful and invasive tests. In comparison, the diagnosis of prostate cancer was viewed as potentially non-threatening due to the relative absence of visible effects and favourable survival rates. Following their diagnosis, men sought to make sense of what had happened and were faced with a series of decisions about their treatment. The treatment phase included coping with the side effects from radiotherapy and hormone therapy, in addition to managing the demands of daily attendance at the treatment centre for radiotherapy. The final theme reflects how men came to terms with cancer in the long-term and how daily life was resumed following treatment. This phase involved negotiating relationships with partners and dealing with an altered sex life, in addition to coping with the impact of late, and sometimes unexpected, treatment effects.

1. Pathway to diagnosis

The pathway to the diagnosis of prostate cancer varied for each participant, with individuals presenting to their doctor for different reasons. The majority reported symptoms such as urinary frequency, nocturia, difficulty passing urine, tiredness and inability to maintain an erection. Although several men initiated the consultation themselves, others were prompted by their wives and some were invited to attend by their GP. Prostate cancer screening was either initiated by the GP or requested by the individual. A small number of men had their prostate cancer diagnosed in the course

of being treated for other medical conditions. A few men had had their PSA monitored for a few years before an elevation in the PSA was detected and prostate cancer confirmed as a diagnosis.

A key finding in this study was men's understanding and knowledge of the PSA test. Although several men reported the importance of the PSA test in being diagnosed, their understanding of the PSA test in advance of it being undertaken was often limited.

“It’s something to do with the numbers. Well I didn’t know...28 what? You know it’s all double Dutch you know...” (Pt. 6)

Some participants were aware that changes to the PSA level were key to understanding the results of the test, and that results can be affected by a range of factors which necessitates caution when interpreting results.

“Perhaps the most important thing with PSA level is not so much the measured amount but the rate of change” (Pt. 14)
“it could be very high, it could be low, it it, it all depends on stress or whatever and I believe if you’ve been riding a bike it’ll alter it again, so, it’s only a guide isn’t it”(Pt. 8)

Other investigational procedures to determine the presence of prostate cancer were a source of distress and disruption to study participants. The digital rectal examination and prostatic biopsy were identified as painful, invasive and a violation of their masculinity. For one participant, the experience was described as worse than having prostate cancer.

“But it’s just a horrible sensation, having that thing grabbing bits of your prostate, it’s kind of ripping bits out isn’t it” (Pt. 3)
“That was the worst, that was the WORST of the whole experience, the biopsy definitely” (Pt. 15)

A biopsy of the prostate was not without complications, with some men reporting symptoms such as discomfort, urinary retention and infections as a result of the procedure.

“You walk into the theatre but you sort of come out in a slightly worse state than when I was walking into the theatre” (Pt. 3)

A key finding in this study was men’s understanding of the PSA test. Although several men recognised the importance of the test, their knowledge of how the test worked varied.

“It’s something to do with the numbers. Well I didn’t know...28 what? You know it’s all double Dutch you know...” (Pt. 6)

“Perhaps the most important thing with PSA level is not so much the measured amount but the rate of change” (Pt. 14)

2. *Receiving the diagnosis*

Not surprisingly, the majority of respondents were shocked to receive the diagnosis of cancer. A few respondents reported that the diagnosis confirmed what they suspected.

You go a bit numb you know...neither of us did we, expected it, neither of us expected it (Pt. 13)

I was already sort of prepared that there might be an unfavourable diagnosis (Pt. 18)

For some participants the invisible nature of the disease proved to be both a help to processing the diagnosis, while for others it induced a sense of stress and hindered adaptation.

When you can’t see what you’ve got you don’t know what’s going on and it’s...you just don’t know what’s going on and it wrecks your head (Pt. 6)

Something that I can't see or that's not tangible or no symptoms, so that's why it hasn't bothered me (Pt. 7)

Participants expressed a range of health beliefs concerning prostate cancer and often attributed their symptoms to non-health threatening causes rather than to illness. Symptoms were often normalised as a consequence of advancing age.

"It's very difficult for men because it happens to normal people anyway, you know, it's not a dead cert symptom because it's a symptom of getting old" (Pt. 12)

Other strategies used to minimize the emotional impact of the diagnosis included situating prostate cancer at the non-invasive, non-aggressive end of the cancer spectrum, enabling these men to articulate being less threatened by the disease.

I mean it's not like very invasive, it's not very life threatening so I mean I don't know how I would have reacted if I'd had pancreatic cancer or something (Pt. 10)

Other men talked about the attitudes they had adopted to deal with the diagnosis. These ranged from a sense of pragmatism and 'getting on with life', to thought-processing, subject avoidance and exercising a sense of humour.

I kind of sort of feel determined to you know cope with it and tackle it head on, I feel determined to beat it (Pt. 3)

Pull the blinds down don't you? You put the shutters down (Pt. 6)

I was a bit shook then but I went out with my mates at the weekend they took the mic out of me and it just stopped it dead...so yeah the lads, if you are having a bevy with them just laugh it off, it works (Pt. 20)

The skills and expertise derived from pre-cancer occupational roles was used to deal with the impact of the diagnosis.

“When you’ve spent 30 odd years at sea you learn to cope with things” (Pt. 24)

“I’ve been a prison officer and I can handle things” (Pt. 15)

It was necessary to balance cautious optimism with the possibility that cancer could return in the future.

Convinced in the back of your mind you’re cured, you know you are not, but you’re convinced that you are cured (Pt. 11)

Information and knowledge were commonly used to come to terms with the diagnosis, such as feedback from the doctor which was used to instil a sense of hope and positivity.

My GP said you probably won’t die of prostate cancer but you will die with prostate cancer like a good many other people (Pt. 18)

3. Making sense of cancer in daily life

Following the cancer diagnosis, participants sought to make sense of what had happened by reflecting on what they could have done differently and how health behaviours could be positively influenced as a result.

You think that something like that will never happen to you ‘cause I mean I don’t smoke (Pt. 6)

I should have gone a bit sooner. I should have maybe realised things weren’t quite normal and in future obviously I would do (Pt. 19)

For one participant, prostate cancer was over-shadowed by pre-existing health conditions.

I certainly wasn't devastated by the fact that I'd got cancer...I think probably ... one of the reasons was that perhaps the heart was taking precedence over it, in my mind (Pt. 14)

4. *Managing the treatment process*

Following diagnosis men were required to make decisions about which treatments to have (surgery, radiotherapy, brachytherapy, hormone treatment, active surveillance and watchful waiting). A number of factors influenced the decision-making process such as the nature of information shared by health care professionals, the extent to which men understood the treatment and the time available to make the decision. Some men wanted others to make the decision for them, but in all cases access to detailed and timely information was crucial for effective decision-making.

"There's another thing I don't agree with, they can't advise you on what to do. It's ... to me it's daft" (Pt. 13)

"I haven't got a clue. I am terrified to ask. I don't know" (Pt. 6)

Participants used a variety of knowledge sources and beliefs when deciding to accept radiotherapy. These ranged from avoidance of potential complications associated with treatment, to understanding radiotherapy as a minimally invasive intervention to physical health and functional ability.

"I have seen prostatectomies and TURs and I think there is a high element of incontinence with it and I didn't want to go down that road" (Pt. 4)

"Thinking about it radiotherapy probably seems like a better option, it seems like a finer tool to me for doing the job" (Pt. 3)

"Whereas I was thinking with the steroids and the radiation I could probably carry on more or less as normal" (Pt. 3)

A key finding in this study was the impact of the pre-radiotherapy preparation regimes on the individual's ability to cope with radiotherapy. The physical and

emotional discomfort associated with bladder and bowel preparation was compounded by having to wait for treatment and lie still on the treatment couch.

“You have drunk your water to empty your bladder etc etc and filled your bladder up again. And you’re sitting there and you’re thinking and its 15 mins and its now 45 and your knees are crossed and your eyes are watering and you think ‘I still have 10 mins before I lie on that bloody table” (Pt. 23)

“Worst part of that was taking the treatment for it first” (Pt. 24)

“The radiotherapy was no problem, it was what you had to do beforehand (Pt. 11)

The degree to which radiotherapy impacted on men’s everyday lives varied. Attending radiotherapy was time consuming, interfered with usual activities and required the re-organisation of life. Strategies were often used to accelerate time and expedite the completion of treatment.

“I couldn’t swim for six weeks. Not because you couldn’t swim, but because the time that you were going to the hospital was when we usually went for a swim” (Pt. 12)

“I’m on shifts but I arranged with work so I could go in and stay on the morning shifts so I would go in to work for 6 o’clock, finish at 10 o’clock, come home get changed go to....and have the treatment”(Pt. 11)

However, for a number of men, the retrospective appraisal of radiotherapy was viewed as unproblematic, since the treatment was not considered to cause discomfort or pain.

“It sound funny for me to say but it was a pleasant experience if you can understand what I mean, to what I was expecting... the actual experience there’s no problem what so ever, no pain nor anything” (Pt. 17)

Well it's not painful, if anything, it's slightly, it's slightly boring because you spend a lot of time waiting (Pt. 13)

The majority of men received hormone therapy in addition to radiotherapy. The majority of men experienced unpleasant effects such as loss of masculinity and sex drive, feminisation of the body, hot flushes and sweats. Changes to masculinity and sex drive were viewed as particularly distressing, while feminisation of the body led to embarrassment.

“Basically the hormones have just diminished all thought, interest in sex, the physical side of it is just impossible” (Pt. 2)

“The symptoms of the hormones is the aches and pains that I've got which are quite debilitating in regard to my muscles in my legs, joints and everything, I'm on painkillers for them” (Pt. 11)

Following completion of radiotherapy, men recalled a range of experiences from not feeling unduly affected by the treatment, to coping with unexpected physical effects such as urinary and bowel problems or fatigue. The occurrence of side effects were often traded off against the benefits derived from radiotherapy.

“Never felt ill or I felt quite good and every time I would go and see the nurses for these recap things, I felt like a fraud” (Pt. 20)

“It's a nuisance getting up in the night but I would rather do that than...in balancing it up you would rather...I would say yeah okay it's a trade-off and that's the way at the moment I will play it” (Pt. 18)

One participant reflected on the emergence of health symptoms after completing radiotherapy. For some men delayed effects were unexpected, but the majority developed strategies for reducing their impact on daily life.

“Well certainly by the end of the treatment I was having to get up in the night... I would rather just sort of get up in the middle of the night than have yet more pills to take.” (Pt. 18)

There were a number of occasions when side effects proved to be better or worse than expected.

“when you have the radio treatment it’ll, it starts to swell and of course if it swells it’ll close up the urethra so I may have problems there” (Pt. 8)

5. Living with prostate cancer in the long-term

For some respondents, the recovery period following completion of treatment involved a series of adjustments to cope with long-term health effects such as tiredness and nocturia. This occurred at a practical and personal level.

“I now very rarely get up during the night...I can control it, if I’m going anywhere I won’t have a big cup I’ll have a smaller cup” (Pt. 22)

Although long-term health issues were accommodated by the majority of respondents, for a few, the physical effects from prostate cancer and its treatment proved to be unexpected and disruptive.

“Over the last 12 months I’ve had proctitis, bleeding through my back passage when I go to the toilet...they said it was probably caused by the radiotherapy and my only concern is that they didn’t tell me that it was possible. So when it first happened, having had cancer, it scared the living daylights out of me” (Pt. 22)

It was not uncommon for men to engage in health-promoting behaviours designed to maximise their survival potential, such as living a healthier lifestyle. For obvious

reasons, cure and survival became a central focal point for men in the study, with ten years being used as a landmark for assessing health outcomes.

With regards to treatment they won't really know if it's been successful until about 10 years time (Pt. 24)

How men approached and managed relationships with those around them, particularly spouses, was an important finding in this study. Spousal relationships were usually the focus for mutual support and influenced the way participants managed their disease. It was not unusual for relationships to be strengthened through experiences. However, while cancer often brought couples closer, it also accentuated any differences in coping responses and adjustment styles.

I think she just worries I think about the outcome, more than I thought she would have done. She never actually expressed it to me (Pt. 17)
There have been times when the wife has said to me you've been more aggressive (Pt. 2)

The resumption of sexual activity was a significant issue for many respondents. The physical and emotional consequences of prostate cancer impacted on the individual's masculinity, identity and sense of self-worth.

"You've lost a bit of your manhood, but like I say, your health's more important than that" (Pt. 17)
I suppose some men would feel oh gosh it's ruining my life or whatever, maybe not feeling a man anymore but it certainly isn't an issue with me (Pt. 10)

A variety of approaches were taken to dealing with physical symptoms such as erectile dysfunction. While some men adopted measures to rectify loss of sexual function, others minimised its impact as a shared decision with the spouse and a consequence of advancing age. However, it was less apparent how the distress and sense of loss expressed by participants was resolved or managed.

Well of course...with the treatment and all...you lose your sexual relationship and all that...but that does not worry us at our age. I'm 68 (Pt. 15)

It's affected my wife in the respect that...you know, our love life and that has really affected her to be perfectly honest, yeah it has upset her... I feel sorry for her if you know what I mean (Pt. 20)

She's...a fair bit younger than me so it's not been great but she's been great. We've accepted it. What else can you do? (Pt. 11)

A number of participants sought to maintain their sex life by seeking medical intervention or using alternative means of arousal.

"The physical side of it is just impossible, I've been and had the sex therapy, whatever you want to do, we can give you pumps, we can give you tablets, I've had the tablets, it worked at first and what happened then it was just no interest whatsoever"(Pt. 11)

A range of support systems were used to aid coping and positive emotional adjustment to cancer. The spouse, family, friends and finances were all regarded as important sources of help that made life easier.

I dunno how well I'd have coped without her in effect (Pt. 23)

You are relying on your mates to a certain extent and the family and what little savings and a little bit of help from the bank. That's how we got through it (Pt. 23)

You know that people are there if you need them (Pt. 10)

DISCUSSION

The study findings highlight a number of important issues to the health and wellbeing experiences of men with prostate cancer from diagnosis, through treatment and into the survivorship period following treatment completion. It was apparent that triggers

for help seeking ranged from active engagement with health services in response to specific symptoms, to passive help seeking based on prompting from others. In some cases, help seeking was targeted at other symptoms which resulted in the opportunistic detection of prostate cancer. It would appear that this is a similar finding to other studies on cancer detection (Wall et al, 2011) which highlights the need for a rigorous strategy for developing more effective early help seeking behaviours to aid cancer detection. Furthermore although a range of health beliefs were identified, our study showed that men often attribute their symptoms to less-threatening causes such as a consequence of old age. This highlights some of the difficulties experienced by individuals when differentiating between cancer and less serious illness and raises the question of what initiates men to seek help for their prostate symptoms. It may be as Wall et al. (2011) suggests that a combination of factors stimulate help seeking behaviour rather than specific symptoms alone and the emotional response to the symptom may influence the attribution made, all of which requires further investigation.

Traditionally, men have been portrayed as reluctant to talk about their health and to seek health advice from professionals for health problems (Wenger, 2013; Vogel et al, 2011; Yousaf et al, 2013). Men in our study shared their experiences with other men within various social contexts e.g. pubs and hobby clubs, often encouraging them to seek advice for health issues. Peer support was commonly valued as an outlet for emotions and provided opportunities for camaraderie, collective endeavour and the mutual desire to help others. The relationship with healthcare professionals was also important, particularly the Consultant who was instrumental in the negotiation of solutions to health problems. Indeed, Berger et al. (2013) made a similar observation concerning the impact of social settings on men's willingness to talk, although they acknowledge self-selection bias in their sample. The findings from this study support the development of gender-specific and gender-sensitive settings and environments through which men can be encouraged to become health aware by talking about their health experiences.

We also found that men valued practical and emotional support from their spouse and family, contrary to other research where men were less likely to access social support

and receive emotional help from their relationships, preferring information exchange over emotional connection (Clarke et al 2006). However, our findings do support those of Carlson et al. (2001) and Greeff & Thiel (2012) who found that men rated the emotional support obtained from their spouse and family of primary importance. Similarly, in a UK study of men's experiences of radiotherapy for prostate cancer, Kelsey et al. (2004) found that family were viewed as the primary source of support, followed by friends and work colleagues. There was little evidence in this study to suggest that men viewed support groups as significant to their disease experiences, with most informal support being obtained from pre-existing networks. The findings from a Dutch study by Voerman et al. (2007) may partly explain this, as support group participation was found to be highest amongst younger men, those with little social support and those with a positive orientation to groups.

Men in this study used a range of coping strategies consistent with the literature on masculinity and gender norms. While some participants reported avoiding talking or thinking about cancer, others proactively managed their disease by altering their behaviour and engaging with health services. These findings are in line with existing research which locate men's health behaviours within the context of male socialisation and gendered constructions embedded in western culture (Chapple and Ziebland, 2002), where becoming ill and losing control over the body is viewed as a threat to masculinity (Gray et al, 2002). In addition, men are more likely to adopt a stoic attitude to health matters and to use pragmatism, humour and avoidance to ease distress and feelings of emasculation (Gray et al, 2002; Wall and Kristjanson, 2005; Oliffe et al, 2009). Cultural norms dictate the nature of the masculine role in society and the behavioural traits expected of men i.e. the man as provider, 'breadwinner' and protector of the family. Consequently men's actions are wired into a set of socio-cultural values which may generate barriers to their effective engagement with health issues. A study by O'Brien et al. (2005) reports how men often require pressure from others, particularly spouses/partners to engage in health behaviours, as this provides a way of legitimising and preserving their masculine identity. In addition, men may seek preservation of their masculine identity through, for example, the confirmation of a diagnosis in order to continue in masculine roles, particularly those requiring physical strength (O'Brien et al 2005; Maliski et al. 2008). Indeed, we found that

some participants identified pre-cancer occupational roles as a way of coping i.e. macho occupations that required resilience and fortitude and which could be applied in the same way to managing the disease situation.

Participants in our study accessed a range of individualised, internal coping mechanisms to manage their disease. It was not uncommon for men to re-prioritise their lives by altering plans and adopting new lifestyle routines, reconfiguring life to accommodate their condition. In cases where there was long-standing illness or disability in the participant or their spouse, coping was embedded in the usual way of managing health problems, where events became normalised and, in some instances, the cancer took second stage. This finding illustrates how men may draw on a range of pragmatic considerations when managing their disease experience.

An interesting finding from this study was the impact of men's perceptions of prostate cancer as a potentially non-threatening disease associated with few symptoms and a positive prognosis. Knowledge of prostate cancer through the direct experience of the disease was used by several participants as a way to rationalise and explain their responses. The diagnosis was often compared to other diseases which rendered it less problematic, for example other cancers considered more aggressive or chronic disease states viewed as more troublesome such as rheumatoid arthritis and ankylosing spondylitis. This mirrors research by Carter et al. (2011) in their study of supportive care needs in patients with advanced prostate cancer, where individuals considered themselves fortunate not to have a worse cancer. These findings may not be surprising given the improved survival statistics and treatment control for early stage prostate cancer compared to other cancers. Participants in this study were receiving curative treatment and some had long-term co-morbidities that pre-dated their cancer diagnosis, causing a range of debilitating health symptoms which impacted negatively on their quality of life. In comparison, some participants viewed prostate cancer as a *secret* disease, not associated with pain, visible swelling or incapacity. This finding is consistent with other research by Chojnacka-Szawlowska et al. (2013) and Soler-Vila et al. (2011), where beliefs about cancer were shaped by perceived risks concerning its curability and self appraisal of health status. A positive appraisal of personal health and believing that the cancer could be effectively controlled was associated with

positive psychological adjustment in patients, compared to increased anxiety and depression in patients who believed that their cancer was incurable.

Our study highlighted the impact of investigational and treatment factors on how men came to terms with their diagnosis. Participants in this study demonstrated heightened anxiety and distress concerning the invasive and painful nature of rectal examinations which for some men were considered worse than the experience of prostate cancer as a whole. Several studies have described the reasons why men find the digital rectal examination and rectal probe problematic and a threat to their masculine identity (Rivera-Ramos and Buki, 2011; Oliver, 2007; Winterich et al, 2009). In a UK study by Kelly (2009) the intimate nature of diagnostic procedures was associated with trauma and a breach of the boundaries of the physical body. This study used an ethnographic approach to explore the experiences of 14 recently diagnosed men with prostate cancer. Men were interviewed and observed during clinic consultations and treatment episodes over a period of eighteen months. Findings from these studies identify the anal zone as sacred to heterosexual men, where anal penetration is viewed as a homosexual act and a violation which threatens the normative notions of manliness and leads to stigma, fear and devaluation. This study highlights the need for health messages to take into account the meanings attributed to rectal examinations in men and for professionals to present information in a way that emphasises the psychological, emotional and practical aspects of such investigational procedures. We suggest further research to explore the impact of the rectal examination on men's perceptions of prostate cancer and how the investigational journey can be managed more effectively through therapeutic interventions to aid positive adjustment and coping.

The effect of altered sex life associated with the diagnosis and treatment of prostate cancer is explored in several studies (Arrington, 2008; Wenger and Oliffe, 2012) and was important to men in our study. It was not uncommon for men to explain the loss of their sex life as a consequence of old age or as a mutual decision made with their partner, a finding discussed in a study by Maliski et al. (2008). However, acquiescence or downplaying sex did not occur without consequences for the individual. Participants expressed grief concerning the reduced opportunities for

intimacy and being attractive to the opposite sex, often being more concerned about the impact on their spouse. This was particularly apparent in a small number of men in the study who lived alone and felt that their chances of meeting anyone might be compromised by their situation. This finding mirrors a US study by Kazer et al. (2011) who found that unpartnered men were more self-reliant and may experience difficulties when pursuing new relationships due to embarrassing symptoms. The study conducted interviews with seventeen unpartnered prostate cancer survivors, however study limitations included recall and selection bias.

The issues associated with being single and managing prostate cancer merit further investigation, and how needs may differ from men who are in relationships. Exploratory studies can assist in providing a broader understanding of how marital status impacts on quality of life and lifestyle choices following diagnosis and beyond into the survivorship period. Existing research suggests that single men are less likely to seek help on health matters (McDowell et al, 2013) and are more likely to engage in health risk behaviours, whereas married men are more likely to seek curative treatment, live longer and experience better QoL associated with spousal support (Alsadius et al, 2013; Abdollah et al, 2011; Gore et al, 2005). In contrast, Bergman et al. (2009) reported on the correlation in mental health outcomes amongst partnered and unpartnered men and found this to be comparable, except in the domain of fear of disease recurrence which was higher for unpartnered men.

The PSA test dominated many participants' narratives as individuals sought to interpret their results and relate this to their condition. It was common for men to focus on the numerical values derived from the test, the extent to which these changed over time and how the results compared to those of other men. Indeed, Oliffe and Thorne (2007) make the point that men will often self-direct their knowledge of prostate cancer through the use of biomedical language and numerical markers when describing and explaining their disease. As Ervik & Asplund (2012) state, "*numbers and figures are concrete, the test results become something to hold on to and may allow patients to feel some measure of control in a chaotic, emotional situation*" (pg. 107). Awareness and knowledge of the PSA test has been found to vary amongst men and yet this is one of the diagnostic markers used to confirm and track the presence of

disease. In our study some men had not been informed about the test, while others were aware of the test and sought detailed information in order to make an informed decision which is consistent with research by McDowell et al. (2013). It was apparent that the test was offered by the GP through direct request or on the suggestion of the doctor, which mirrors current PSA screening practices questioning the reliability and efficacy of the test (Leader et al, 2012; National Cancer Institute, 2012; Macmillan, 2013). This study suggests that the implications and consequences of commencing PSA testing need to be adequately understood by individuals through improved education and counselling, as recommended by Dube et al. (2005) and Burford et al. (2009). This should include information on the risks associated with prostate cancer screening, such as bleeding or infection (Ferrante et al, 2011) and an understanding of the patient's personal beliefs and prior knowledge of investigational procedures.

Following their diagnosis, men identified treatment as a component of coming to terms with their disease. This study highlighted the different coping strategies required to deal with radiotherapy as opposed to hormone treatment. Consistent with the literature, hormone therapy created a range of physical and emotional needs in men associated with feminisation, hot flushes and altered sex drive (Carter et al, 2011; Grunfeld et al, 2012; Eziefula et al, 2013). Indeed, men in this study described strategies for dealing with the embarrassment associated with an altered body image caused by hormone therapy, commonly using concealment to hide affected areas. Radiotherapy, on the other hand, is known to produce gastrointestinal symptoms and impairment of urinary or sexual function (Hedestig et al 2005). In contrast to hormone therapy, radiotherapy involved dealing with late, and sometimes unexpected, side effects. Delayed side effects are a common occurrence following pelvic radiotherapy and occur up to six months following completion of treatment, sometimes extending up to a year or more (Macmillan, 2012). These include tiredness, sore skin, bladder and bowel irritation and changes to sexual function (Cancer Research UK, 2012; Queenan et al, 2010). A number of participants in the study described debilitating symptoms which impacted significantly on their quality of life and well-being, for example bleeding, nocturia and fatigue. Various strategies were used by men to overcome these, such as regulating daily fluid intake and taking periods of rest. Further investigation into the impact of late radiotherapy effects on men's daily lives

is supported by Ervik & Asplund (2012), as well as the development of supportive interventions to help men deal with the impact of potentially stigmatising and isolating symptoms.

For the majority of participants, radiotherapy required logistical co-ordination and planning to meet the daily treatment schedule, often involving the re-organisation of routines and roles. The impact of the radiotherapy regime on men's daily lives has been relatively underexplored in the literature, where attention has largely focused on the availability of information, support and management of treatment side-effects during and after radiotherapy (Queenan et al. 2010; Adler et al. 2009). However, a UK study by Kelsey et al. (2004), found that men receiving external beam radiotherapy often developed closer relationships with the radiotherapy staff due to frequent attendance at the treatment centre. They conducted focus groups with men who had recently completed a course of radiotherapy for localised prostate cancer. Indeed, men in our study appreciated the camaraderie and approachability of the radiotherapy team in making the atmosphere of the treatment centre less threatening and more personal. A Swedish study by Oster et al. (2013) came to similar conclusions in a small study of men with newly diagnosed prostate cancer who were receiving curative radiotherapy. They found that men generally experienced a positive sense of reassurance through the supportive interventions of radiotherapy staff, however this had to be balanced against the likelihood of men feeling uncertain and embarrassed by examinations before radiotherapy. An important finding from this study was the impact of the pre-radiotherapy regime on the health and well-being of participants, particularly the self-administration of enemas/suppositories for bowel clearance and the need to maintain a full bladder. Some participants found this part of the treatment stressful and uncomfortable, which highlights the need for further research into the structural and organisational aspects of radiotherapy and the impact they have on men's health and well-being.

Current evidence suggests that patient's knowledge and understanding of radiotherapy is limited, but may be improved through better information and positive media messages (Hammick et al, 1998). This should include the way in which men make decisions about receiving radiotherapy and how the treatment is viewed in the context

of other treatments for prostate cancer, for example as an intervention that is targeted, precise and minimally invasive to health and functional ability. However, this study highlighted how men's beliefs about radiotherapy influenced their treatment choice. The potential discomfort and side effects associated with radiotherapy were traded off by some men against the prospect of being cured and receiving a relatively pain-free intervention. Treatment decision-making in relation to prostate cancer has been subject to extensive investigation, including the extent to which the patient shares this responsibility with the healthcare team and vice versa (Sinfield et al, 2009; Hedestig et al, 2005). In a qualitative UK study by Cohen and Britten (2003) barriers to shared decision-making included the paternalistic attitude of the doctor and the patient's unwillingness to appear disrespectful or to take responsibility for treatment outcomes. The conclusions drawn from this study suggest that consultations with patients about radiotherapy should focus on patient expectations and motivations and how the patient plans to manage their treatment and rehabilitation experience. This could assist healthcare professionals to identify the barriers and opportunities for promoting a positive healthcare experience amongst patients and their family members, thereby maximising the individual's quality of life and well-being.

CONCLUSION

This study successfully identified several key themes that are relevant to the way care and treatment are organised for men with a diagnosis of prostate cancer. The various stages of the diagnostic and treatment pathway give rise to a range of unique and diverse influences on the physical, emotional and social wellbeing of men and their informal networks. The impact of investigational procedures emerged as particularly significant in how men adjusted and coped with their diagnosis. Healthcare professionals need to be alert to interventions that will adequately prepare and support men to undergo invasive and often painful procedures, whilst providing information that will enable informed choice and decision-making. The results of this study suggest that further work is required to understand men's experience of radiotherapy and how the treatment impacts on masculine identity. It is important that staff assess patient needs particularly in the domains of sex life and the long-term impact of treatment-related side effects. Finally, the study reinforces the need to take account of

the patient's viewpoint through more prospective studies, rather than focusing wholly on clinical outcomes.

STUDY LIMITATIONS

This study used a constructivist grounded theory approach to explore men's experiences of prostate cancer and health services. Although it adds to the previous body of knowledge by providing an interpretative understanding, the limitations of the study should be recognised. Participants were recruited from one cancer centre and, as such, it could be that local factors may have affected the patient experience. Only participants receiving external beam radiotherapy were included in the study. Furthermore some men underwent additional treatments and their experiences may have been affected by these. A cross sectional sample was used with different men at specific points of time. There may have been different findings if a longitudinal design had been used with the same men over a period of time.

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CONFLICT OF INTEREST

There is no known conflict of interest for any of the authors associated with this paper.

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