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The lived experience of adjustment to prostate cancer

Abstract

This study aimed to explore the lived experience of adjustment to prostate cancer following diagnosis. A qualitative, Interpretative Phenomenological Analysis (IPA) approach was utilised. Data was collected through semi-structured interviews. A purposive sampling method recruited 8 participants from a North East of England based, patient-led prostate cancer support group. Participants were diagnosed with prostate cancer and had received a range of treatments. Participants ranged from 59-80 years of age, (mean age = 69), and time since diagnosis ranged from 13 months to 8 years. Data were analysed in accordance with an IPA approach. Four themes were generated: 'Living with Uncertainty/PSA test worry'; 'Renegotiating Masculinity'; 'The Prostate Champion' and 'Humour'. Themes were related in their dynamic nature, which involved participants actively negotiating the adjustment process. The findings highlight the complex nature of the adjustment process to prostate cancer and provides in-depth insight into the barriers and facilitators participants experienced.

Keywords: *'Adjustment', 'Interpretative Phenomenological Analysis', 'Prostate Cancer', 'Phenomenology', 'Qualitative'.*

Impact Statement: Prostate cancer is a leading cause of male morbidity and mortality in the UK. The adjustment process can be affected by a multitude of physical and psychological factors. Prostate cancer can result in psycho-social

issues which may lead to maladjustment. In exploring experiences of adjustment to prostate cancer, this research demonstrates men's negotiation of the adjustment process. Men renegotiated their sense of masculinity in accordance with physical and psychological impacts while experiencing uncertainty and future worries. Humour and providing social support to others were identified as facilitators to adjustment. This research provides insight for healthcare professionals working with men with prostate cancer and highlights ways in which adjustment can be influenced and positive adjustment facilitated.

Declaration of Conflicting Interests: The Authors declare that there is no conflict of interest.

Introduction

Prostate cancer is a leading cause of male mortality in the United Kingdom (UK) with the latest published figures highlighting that 11,287 males died due to the disease in 2014 (Cancer Research UK, 2015). The disease, which generally affects older aged males (Chambers et al., 2015), is highly treatable if diagnosed early through prostate specific antigen testing, and survival rates indicate that 84% of males commonly live longer than a decade following diagnosis (Carlsson & Vickers, 2015; King et al., 2015).

Treatment options are based on the progression of the disease and factors specific to the male, such as: life expectancy, comorbidities and physical health (Gacci et al., 2009; Heidenreich et al., 2014). Stages of disease progression are localised (within the prostate), locally advanced (spread from the prostate to nearby tissue), and advanced (spread to other parts of the body). Physically, across all treatment types, quantitative literature indicates that the adjustment process can be affected by deterioration in sexual functioning (Donovan et al., 2016; Quinta-Gomes, Janssen, Adaikan & Nobre, 2017) with males reporting decreased libido, changes in orgasm and erectile dysfunction (ED) as expected side effects (Salonia et al., 2017; Walker, Wassersug & Robinson, 2015). Furthermore, incontinence and bowel problems are reported by males who opt for radical prostatectomy/radiotherapy and hormone treatment can cause fatigue, mood swings and changes in bodily composition, all of which may also hinder the adjustment process (Elliott et al., 2010). Alongside the physical, prostate cancer can also create substantial psycho-social issues for males, with self-esteem (Else-Quest, LoConte, Schiller & Hyde, 2009) and concepts of identity (Appleton et al., 2015; Eziefula, Grunfeld & Hunter, 2013) being challenged. These factors, if not appropriately managed, may lead to maladjustment and the

subsequent developments of anxiety, depression and other psychological disorders (Mehnert, Lehmann, Graefen, Huland & Koch, 2010; Sharpley, Bitsika & Christie, 2009).

Considering the expected longevity of life following diagnosis, appropriate negotiation of the adjustment process is key (Sharpe & Curran, 2006; Walsh et al., 2018). Regardless of the specific form of prostate cancer diagnosed, and subsequent treatment path chosen, adjustment begins at the onset of the disease (Sharpe & Curran, 2006), impacting management of the dynamic physical, psychological, social and spiritual challenges prostate cancer can present (Hanly, Mireskandari & Juraskova, 2014; Yanez et al., 2009). Adjustment is broadly conceptualised as both a state and an internal psychological process which occurs over time (Brennan, 2001; Lazarus, 1969). Whilst coping theory posits that adjustment is based on emotion focused coping (Lazarus & Folkman, 1987) and involves the development of behavioural strategies to manage the inevitable traumas associated with a cancer diagnosis (Brennan, 2001). From a social-cognitive view (Bandura, 1986), the adjustment process challenges individuals to adapt themselves and their social world to make sense of the changes cancer and treatment initiates (Lepore, 2001).

Within the field of psycho-oncology, whilst the term 'adjustment' is widely used and viewed to be of central importance to the lived experience of cancer (Brennan, 2001), research has predominately been quantitative in nature (Bloch et al., 2007) and focussed on the psychometrically measurable 'achieved state' or 'endpoint' of adjustment as opposed to the complex process males engage in to reach that point (Sharpe & Curran, 2006; Stanton, Revenson & Tennen, 2007).

That said, one qualitative review (Spendelow, Joubert, Lee and Fairhurst's, 2017) of eighteen studies examining coping strategies for prostate cancer patients identified quality concerns including insufficient sample information, which limits research transferability (Lincoln & Guba, 1986) and a lack of evidence regarding the researcher's reflexive attitude. Despite these issues however, Spendelow et al (2017) found some consensus emerging within the qualitative literature which suggests that masculinity, cognitive adaptation and uncertainty are fundamentally involved in the adjustment process.

Given the biological changes in males (Simkins, 2002) and side effects often of a sexual/intimate nature (Wasserug, Westle & Dowsett, 2017) males may often call into question their 'sense of self' and in turn their expression of masculinity during adjustment to prostate cancer (Maliski, Rivera, Connor, Lopez & Litwin, 2008). There is conflicting research in this area as adjustment to prostate cancer often begins at an age when male's expressions of masculinity can diversify from sexual potency and health to alternative aspects of life such as social status and wealth (Olliffe, 2005; Tannenbaum & Frank, 2011). However, as argued by Burns & Mahalik's (2007) synthesis of qualitative research specific to adjustment, for some PCA patients several additional barriers may disrupt the adjustment process. For instance, males may hold the ingrained assumption that they can cope and adjust to prostate cancer (Wall & Kristjanson, 2005). Thus, as prostate cancer treatment is likely to limit patient's ability to sexually perform (Quinta-Gomes et al., 2017), negative emotions such as shame and humiliation can develop through the reduced capacity to provide penetrative sex (Donovan, Walker, Wasserug, Thompson & Robinson, 2015). The capacity to provide penetrative sex is considered as an indicator of masculinity for males whose characteristics, behaviours and overruling

identity presents as hegemonic (Wall & Kristjanson, 2005; Cecil, McCaughan & Parahoo, 2010). Hegemonic masculinity is also associated with traits such as emotional resistance, dominance, assertiveness and control (Evans, Frank, Oliffe & Gregory, 2011).

It has been suggested that males perceive that bodily changes are developmentally normative as an aging male (Gannon, Guerra-Blanco, Patel & Abel, 2010) and that side effects of treatment may be perceived as a short term barrier to adjustment, creating a beneficial illusion for prostate cancer patients (McSorley et al., 2014).

While these studies focused on masculinity and coping respectively as opposed to directly exploring how these perceptions influenced the process of adjustment the ability prostate cancer patients may have to positively reframe experiences is suggested to lead to personal growth (Hagen, Grant-Kalischuk & Sanders, 2007).

This may facilitate the adjustment process, as males make sense of their cancer (Wenger, 2013). However more adjustment specific research is needed to support this theoretical assumption.

Although 'positively reframing' experiences may benefit prostate cancer patients following treatment (Spendelov et al., 2017), in the early stages of diagnosis dealing with the uncertainties prostate cancer presents, may be key to adjustment (Wellam & Degner, 2008). As highlighted by Bailey, Wallace & Mishel's (2007) qualitative description of patients undergoing active surveillance, the ability to adjust was hindered by prostate cancer patient's limited experience of treatment related side effects and concerns over disease progression, which created uncertainty. Whilst, Bailey et al's (2007) findings are useful in understanding uncertainty, their focus on participants descriptions through content analysis, may have lacked the interpretive depth necessary to truly uncover how their participants experiences of uncertainty,

influenced their adjustment process (Elliot, 2005). Importantly, more interpretatively focussed qualitative research can help uncover how uncertainty influences the adjustment process (Gough & Robertson, 2010).

Currently, one of few studies in the field that emphasises interpretation through the use of Interpretative Phenomenological Analysis (IPA), explored the strategies that five patients utilised to preserve their wellbeing following diagnosis (Levy & Cartwright, 2015). The findings suggest that males took active steps to manage their wellbeing through dealing with several uncertainties and a reduced future perspective (Levy & Cartwright, 2015). However, the transferability of these findings is limited solely to their sample of advanced prostate cancer patients who may have different experiences to localised and locally advanced prostate cancer patients (Breitbart et al., 2010). Similarly, Krumwiede & Krumwiede's (2012) use of IPA, with the aim of informing oncology nurses, uncovered ten prostate cancer patients complex struggle to deal with the uncertainties of the body and highlighted the importance of understanding male's unique perceptions of their prostate cancer experience to help individualise care. Whilst both these studies are useful, they have not been designed with the aim to explore prostate cancer patients lived experiences of adjustment specifically.

There is scope to apply Interpretative Phenomenological Analysis (IPA) to directly explore the lived experience of adjustment to prostate cancer (Gough & Robertson, 2010). The study objective was to understand the process of adjustment for prostate cancer patients through asking the research question: "What is the lived experience of adjustment to prostate cancer?"

Method

Design

A qualitative approach was adopted to gain a deeper understanding of factors which may influence prostate cancer patients throughout the adjustment process. Among the limited qualitative studies reported, there is a paucity of research which utilises IPA as a methodological approach to directly explore prostate cancer patient's adjustment experience. IPA can enable the researcher to focus on the prostate cancer patient as the expert of their own condition (Smith, 2015) and through the use of the 'double hermeneutic' gives the researcher an active role in interpreting how prostate cancer patients make sense of their own lived experiences (Smith & Osborn, 2008). This is important as the interpretative element of IPA could be particularly effective in uncovering the complexities of the adjustment process and understanding the barriers/facilitators to adjustment, some males can find difficult to openly discuss (Oliffe & Mróz, 2005; Witty et al., 2014).

Participants

Eight participants (aged 59-80, with a mean age of 69 years) were recruited via purposive sampling. This sample size enabled the researcher to become immersed in the participant's worlds (Crouch & Mckenzie, 2006) and conduct IPA meticulously through in-depth case by case analysis (Smith & Osborn, 2008). All participants were white British males diagnosed with prostate cancer (three localised; one locally advanced; four advanced). Seven out of the eight participants were married and all participants reported to be either retired or unfit for work. Participants were recruited following a presentation of information about the study to members of a monthly,

patient-led, North East of England based prostate cancer support group. Time since diagnosis ranged from thirteen months to eight years and participants had received a range of different treatments (Table 1).

INSERT TABLE 1

Ethical approval

Ethical approval was obtained from Teesside University School of Social Sciences, Humanities and Law Research Ethics Committee and adhered to ethical guidelines set forth by the British Psychological Society (Standards and Guidelines BPS, 2018). All participants provided written consent prior to interviews taking place.

Materials

Interviews were guided by a semi-structured interview schedule that was piloted and constructed based on knowledge gained from the literature and the first author attending several prostate cancer support group meetings. Interviews began with the question “when were you diagnosed with prostate cancer?” which prompted participants to begin to describe their process of adjustment. The following open-ended questions addressed aspects of the patient’s life pre, during and post diagnosis, to foster a complete understanding of factors which may have influenced participant’s adjustment experience. Questions were designed to probe specific constructs relevant to prostate cancer adjustment including identity, “what’s your identity like as male now?” and support, “has your support network changed?”

Procedure

Once identified at the support group, potential participants were given a study information sheet and the opportunity to discuss the project with the lead researcher. Interviews were arranged via telephone and to facilitate discourse around sensitive topic areas (Oliffe, 2010) interviews were conducted at appropriate prior agreed locations including participant's homes and at the university. Individuals who agreed to participate provided written informed consent. Interviews were audio taped and lasted between 30 to 60 minutes. Upon interview completion, participants received a debrief sheet which included signposting information to a range of prostate cancer specific support services. Audio files were transcribed verbatim.

Data analysis

Interview data was analysed using IPA (Smith, Flowers & Larkin, 2009) in order to explore prostate cancer patients' adjustment experiences. The researcher immersed themselves in the data through multiple readings of each transcript which were read line-by-line and phrases were highlighted that were considered to represent the lived experience of adjustment. Highlighted phrases formed the basis of emerging themes, which developed through exploring each transcript 'as a whole' and 'in parts' to further identify connections between themes (Kafle, 2013). Emerging themes were clustered together in a table of themes and the subjective lived experiences across the sample were identified.

Due to the sensitive nature of prostate cancer as a subject (Oliffe & Thorne, 2007), the male lead researcher kept a reflexive journal throughout the research process to

enhance self-awareness, recognise bias and provide context to methodological decisions (Tracy, 2010). An audit trail was created to increase the transparency of the researchers' decisions and achieve confirmability (Leung, 2015). Considering the importance of the researcher's interpretations to analyse participants lived experiences of adjustment, it was essential that steps were taken to increase the trustworthiness of data (Cope, 2014). Informed through Guba's (1981) framework for establishing trustworthiness, member checking was completed with a group of participants, to increase research credibility through actively checking the accuracy of findings and the researcher's interpretations (Lincoln & Guba, 1986o). The first two authors analysed the research data. All participants were allocated a pseudonym.

Results

From the data, four main themes were generated: 'Living with Uncertainty/PSA test worry'; 'Renegotiating Masculinity'; 'The Prostate Champion' and 'Humour'. All themes were related in their dynamic nature, which involved participants actively negotiating the adjustment process.

Living with Uncertainty/PSA test worry

Throughout the adjustment process participants had to live with the challenge of dealing with the uncertainties prostate cancer presented and PSA test worry was integral to this. PSA testing is non-diagnostic testing which forms part of routine monitoring following discharge from Consultant-led (hospital) care into primary (GP) care, and can lead to diagnosis through identifying the need for further testing (e.g. biopsy, MPMRI scanning) (Merriel et al., 2019). For many, PSA tests presented a

psychological barrier to adjustment which not only arose closer to routine testing but remained a worry in participant's minds in daily life.

Due to the invisibility of prostate cancer within the body, Gary explains that when he goes for his routine PSA test, due to active surveillance following radiotherapy, he feels an unavoidable fear that his PSA score may have increased in the three months since his last test. This fear, although minimal, is repetitive for Gary and it has become a normal part of his life.

The only trepidation is every time you go for the PSA you worry that it has gone up and apparently talking to different people it's a natural reaction because it's the only guideline you've got that something's wrong. (Gary)

This same worry is expressed by Tom who explains that although he is now monitoring his condition, he is still worried that his PSA score never completely went down to zero following his radiation treatment. Despite his PSA score being at a negligible level, his worry has persisted into the later stages of the adjustment process and Tom still is unsure about the concentration of PSA within his blood and the associated risk.

I had four radiation treatments because the PSA didn't go to zero so almost exactly a year later I had 20 doses of radiation and the following September [...]it hasn't gone back to zero but that's a little bit of a niggle at the back of mind I think rather than anything else it has to go back to zero. (Tom)

Paul knows that PSA tests are not completely accurate, yet he still greatly values the importance of his PSA score as it's the only indicator of change he has at his disposal. Therefore, when Paul learned of new research from a monthly visit to his support group (a useful source of information for Paul) that his PSA scores may be

'masked' by the hormonal therapy drug he was receiving, it added to feelings of uncertainty created by prostate cancer and temporarily devalued the importance he previously placed on the PSA score.

I rely so much on my PSA and it's not 100% because there was a newsletter around on the PC group and It was enzalutamide which I'm on can mask the PSA result right so obviously something like that was happening to me because my PSA was still 0.1 but I had cancer in my ribs so why wasn't it detecting it. (Paul)

Even in the later stages of adjustment following discharge from the consultant, Gary hoped that his PSA wouldn't rise again as this signal may infer his cancer has returned.

Since then I've had one blip on my PSA it went up by a .05, I phoned the consultant and he phoned me straight back he said don't worry about it it's PSA bounce (Gary)

Overall, participants place value on PSA testing however, the unreliability of PSA test scores created a sense of uncertainty that provoked worry in participants. This added to the uncertainties and the lack of control participants experienced throughout the adjustment process and created a barrier that may prevent participants reaching an appropriately adjusted state.

Control could also be obtained from other people in support networks, specifically, health professionals. The regular contact Clive had with health professionals due to being part of a clinical trial, provided him with a sense of security and an additional source of knowledge. This enabled Clive to feel ever-present and ready to respond when his cancer mutated, and treatments began to lose effectiveness, or his bodily functions changed.

I was delighted to get on the (clinical) trial for the simple reason that I would be then monitored regularly [...] if the cancer does come back I will be the first person to know (Clive)

Renegotiating Masculinity

The prospect of experiencing biological and psychological changes due to prostate cancer treatment side effects presented a challenge to participant's masculinities as they learnt to adapt to life as a new man. Also, participants expressed responses to perceptions of prostate cancer in the body which highlight the active nature of the 'fight' against prostate cancer.

For participants who had experienced side effects from treatment which changed their bodily functions, they had to adjust to living life in a new body. This not only created a physical challenge to overcome, but also a challenge in which participants had to deal with the effect of a diminished sexual desire within their marital relationships.

For Paul this change was abrupt, and his love life totally changed following treatment.

Oh yeah [it affects my masculinity] but the wife was great the wife was great erm you know we had an active love life you know and happily married but then it was just within three days of getting my first treatment. Gone. Totally gone. (Paul)

Clive embraced the changes which were brought forth by his treatment path, particularly hormone treatment side effects such as hot flushes, and accepted that his sexual functioning did not solely define him, describing himself as a 'modern-day'

man. This new identity has acted as a facilitator in Clive's adjustment process through recognising his changed role in his marital partnership.

I'm almost like a woman officially like a woman and with the hormone treatment I get hot flushes and stuff what a woman would get so I feel like an honorary woman at the moment and I tend to laugh about that because you have to if you concentrate too much on the fact that you know I am the man the one who goes and keeps the cave safe and go out for the food it's not like that these days. (Clive)

In contrast, George who also underwent hormone treatment differed in his response to side effects and dealt with his diminished sexual desire through devaluing his illness and separating the effects of his treatment from his projection of his 'self'. Although this was a challenge initially, it has enabled George to maintain the former masculine identity he had constructed prior to the prostate cancer diagnosis, whilst still accepting the changes in bodily function he has experienced and eventually learnt to live with.

I didn't think I was any less of a fella or a male it's just an illness [...] it hasn't come back because it classes as a chemical castration [...] it's something you have to get your head around and live with. (George)

Lastly, for Charlie, who unlike Clive and George did not undergo hormone treatment but radical prostatectomy, described himself as once an active man, but now finds it difficult to travel into the local community with his wife due to the physical complications brought on by having a sphincter fitted. Now Charlie is confronted with a socially based barrier to adjustment that makes him wary of going outside as it is vitally important he knows the location and distance to the nearest toilets for when he needs to empty his bladder. This challenges Charlie as his previous perception of his masculinity was constructed through been physically active and his treatment has

created a state of flux were his bodily functions no longer support the construction of the 'self' he once knew.

I usually make a limitation to how long I can be out say if we go downtown we go on the bus your sat and when you stand up the fluid that's holding in your bladder it wants to get out so I've got to rush to the toilets then check the tube press the button release the bladder but er it is awkward at times but at least I'm not carrying I used to carry a bag and pads wherever I went on holiday and it's just downgrading you know it is very from being fit and active er I'm just not like that man. (Charlie)

To sum up, masculinity is an important feature in participants' lives, which can be affected in different ways, based on treatment choice. All participants had to deal with how prostate cancer challenged their masculinity and based on their previous lifestyles and individual treatment paths, participants differed in how they accommodated a changed identity.

The Prostate Champion

A facilitator throughout the adjustment process was identified when participants explained their new found overarching goal of actively helping others with and without the disease. Whilst dealing with the challenges prostate cancer presented participants found positivity in their lives through helping others who were adjusting to the condition.

In the early stages of adjustment, Paul who had not yet informed his wider support network of his prostate cancer diagnosis, perhaps given the recency of this, spoke of how he was initially shocked that people other than his family had found out about his diagnosis. However, in reflection, this turned out to act as a facilitator during his

adjustment process as he is now able to outwardly focus his time and energy on publicly raising awareness of prostate cancer.

I was shocked because it was like just keep it in the family but somehow he (friend and work colleague) found out how I don't know but it was a good thing because then I didn't mind people knowing and now everyone knows you know the press I've been in, the ____, the ____ up our way, TV, you know and it's just spreading the word but I don't take praise for that because I want to spread the word. (Paul)

Similarly, Callum who volunteered his own time to share his experiences in the hospital to help others during diagnosis, recalls a time at the monthly prostate cancer support group meeting where an individual he gave information to, publicly acknowledged his help.

He said to the group er Callum pulled me into this, he got me sorted out from the very beginning" well I thought that's a nice thing to say because I didn't do anything... so, my confidence was over grown more than anything and I started going to and doing these things with yourself. (Callum)

In another case, Clive whose only symptom pre-diagnosis was a small increase in urination frequency, acknowledged his increased knowledge since diagnosis. He has become an expert of his own condition, and with this knowledge, Clive has adopted a positive role actively educating others about prostate cancer, so they can get tested and catch the disease early.

You know from a point of view of educating me you know nobody said go for a blood test, if somebody done that it would of and that's why I'm actively trying to get as many men as possible have a blood test done all it is is a little bit of blood if there's a problem then you can get further tests it's a marker but it could save your life. (Clive)

Through one of the many new contacts Paul has gained since adopting the 'Prostate Champion' role, he has received feedback that he helped an individual catch the disease very early through encouraging them to get a PSA test.

I said you being okay gives me such a lift because you've gone because of me you've caught it early you know I said erm so don't worry about having a positive result so the two guys they go back every six months just to get checked up and they obviously keep in touch and yeah that's that's my aim that's my goal. (Paul)

In summary, being a 'Prostate Champion' enabled participants to raise awareness of PCA and help others through actively communicating their experiences of prostate cancer as experts of their own condition. In turn this created a sense of positivity that helped facilitate the adjustment process.

Humour

Humour was identified as a strategy participant's and their support networks utilised to place a positive twist on challenging experiences. It was identified in the data that humour was employed as a cognitive strategy to help participants process their experiences, feel positive and adjust to prostate cancer. Humour was enacted both by the participants themselves and from their wider support networks.

Tom acknowledges that he is diagnosed with a life-threatening, but slowly developing, disease and through using humour he is able to express his positive belief that everything could be a lot worse than it is and he's is still happy to live his life.

Whenever it hits me and it wears on my mind I think what's the point, if it's going to happen it's going to happen and its one of the most treatable cancers it's one of the slowest growing cancers if you're going to get a cancer it's the one to get I suppose however I'll quite happily give it away if anyone wants it. (Tom)

Alongside maintaining a general positive belief, for some participants undergoing hormone treatment, it is typical for changes in behaviour to occur unexpectedly which create a complete contrast to regular hobbies and routines. These changes are not always serious and for Paul, he was able to utilise humour to speak openly with his doctor about his new found urge to bake; a hobby Paul has never even previously thought of partaking in. These changes in behaviour experienced due to hormone treatment were not representative of Paul's character, however he found it important to embrace these changes with a smile and laugh as viewing such a change differently could negatively impact his continuing adjustment to prostate cancer.

I had the sudden urge to make scones to do a bit of baking and I'd never baked in my life and we were talking so seriously that's the type of guy he is and he just said Paul I can't help you on that one mate it's your hormones and people laugh about it you know and in the situation I'm in and I'm sure the other lads will have told you have to laugh about it you have to be positive because if you're not it'll get you down. (Paul)

Participant's families also used humour to shine a positive light on challenging situations. Pictures sent from Paul's family helped them all to reduce the perceived seriousness of a nuclear bone scan.

I had to have the radioactive injection on my bone scan erm and the family were sending me pictures of the radioactive man having a bit of crack you know, but then I was down I didn't realise that I had to be more positive then you know I didn't realise I could joke about it. (Paul)

Furthermore, an important aspect of the adjustment process is how well participants transition from their past life. Charlie who viewed himself as active for his age before being diagnosed knows that his physically active role as a Grandad is now gone. Although it is tough to accept this, through using humour to blur the line between his current situation and a past experience, he is able to retrospectively share his fond memories of times playing football with his Grandson.

I think my grandson has seen it in me it's really knocked me back because let's say just before I used to be down at 66 year old be on the beach with my grandson he's 25 year old now and I used to be the goalie and he was taking shots at me and I'm 66 year old have you ever heard of 66 year old diving about on the beach (laughter) like I say stupid you know but er he never scored (laughter). (Charlie)

To conclude, humour helped participants and their support networks through the challenges prostate cancer presented and contributed to the general positivity participants felt helped during adjustment. Furthermore, actively helping others gave participants a new found identity as a 'Prostate Champion' that created positive emotions through raising awareness of prostate cancer.

Discussion

The purpose of this study was to explore the lived experience of adjustment to prostate cancer. Through employing IPA, four main themes were identified: 'Living with Uncertainty/PSA test worry', 'Renegotiating masculinity', 'The Prostate Champion' and 'Humour'.

Uncertainty was an underlying aspect of life with prostate cancer from the beginning of the adjustment process. This supports Levy & Cartwright's (2015) suggestion that the lived experience of prostate cancer involves an ongoing lack of control over the body and the side effects of treatment. It additionally adds to Paterson, Jones, Rattray & Lauder's (2015) recent synthesis of studies exploring self-management strategies for prostate cancer which highlighted the prominence of uncertainty during the early diagnosis stages (Bailey et al., 2007; Mishel et al., 2009) and whilst monitoring the condition (Olliffe, Davison, Pickles & Mróz, 2009). The current study extends these findings through suggesting that uncertainty is prevalent for males considerably after the initial treatment stage. Therefore, in accordance with Mishel's (1990) 'Reconceptualised Theory of Uncertainty' this study provides qualitative data to suggest uncertainty can become an integral part of prostate cancer patients lives as they develop ways to feel in control over the ever-changing challenges prostate cancer presents.

PSA testing seemed to present a barrier to adjustment beyond the initial diagnosis stages, which remained a constant source of worry that increased closer to routine test times, presenting similar outcomes to other related studies utilising quantitative and mixed methods designs (Gustafsson et al., 1995; Lofters, Juffs, Pond & Tannock, 2002). These findings provide an insight into how this worry transcends into the lived experience of prostate cancer at different stages of disease progression. This contradicts Hedestig, Sandman, Widmark & Rasmussen (2006)

narrative findings that PSA tests can provide a sense of security that prostate cancer patients can gain confidence from. Recommendations have been made to increase the delivery of education around PSA testing particularly through health professionals (Torta & Munari, 2009) and this study supports this view, considering the importance participants placed on their PSA test results and the worry a potential rise in PSA levels signified despite this test not being diagnostic. A further point of importance is the finding that one of the participants gained specific value from gaining information about new research via the support group. This suggests that there may be benefits gained from information provision and sharing and this was also evident when males discussed the prostate champions.

Participants' constructions of masculinity were integral to dealing with the physical effects of treatment and despite similar demographic profiles participants differed in their personal constructions of masculinity. These differences support Gray et al's (2002) narrative investigation of prostate cancer patients which proposes that whilst most males maintain their hegemonic self, some males can transition into new expressions of 'the self', to help deal with the physical effects of treatment.

In contrast, participants who portrayed their masculinity construction in a hegemonic manner expressed challenges dealing with reduced sexual functioning and physical activity. This may be due to the value some participants placed on sexual activity in their relationships (Burns & Mahalik, 2007; Wall & Kristjanson, 2005). Partners had an important role during adjustment to physical changes. From a dyadic perspective, this finding supports Lavery & Clarke's (1999) assessment of couples coping strategies post prostate cancer treatment which suggests couples work as a 'team', to deal with physical challenges and form a 'shared identity' to facilitate appropriate adjustment (Fergus, 2011). Given males with hegemonic traits

expressed greater difficulty dealing with loss of sexual functioning and letting go of their past physically active life, the current study supports the growing evidence that suggests constricted constructions of masculinity may be detrimental to the adjustment process (Wall & Kristjanson, 2005). In terms of clinical implications, it may be beneficial for clinicians treating prostate cancer patients to consider male's personal constructions of masculinity when making psychotherapeutic decisions (Burns & Mahalik, 2007) to help increase the effectiveness of therapy through a masculinity focused person-centred approach (Bullen & Tod, 2013).

A positive transition was highlighted through partaking in voluntary roles and utilising humour to deal with the difficulties prostate cancer presented. The methods in which participants helped others and raised awareness of prostate cancer echoes Van Der Spek et al's (2013) findings obtained from cancer patient focus groups which suggest some cancer survivors obtain meaning in life following diagnosis through positive actions and 'leaving a legacy' from which to be remembered. As it is common for cancer patients to perceive feelings of meaninglessness within the initial stages of adjustment (Thornton & Perez, 2006), participants use of the 'Prostate Champion' identity to find meaning, supports the growing quantitative and qualitative evidence which suggests finding meaning is an important factor to consider in relation to the adjustment process (Roberts Lepore & Helgeson, 2006; Spindel et al., 2017; Stanton et al., 2007). Also, being a 'Prostate Champion' was predominately a social role which gave participants a voice to talk openly about their experiences with people beyond their initial support network, which may have decreased isolation and subsequent detrimental intrusive thoughts (Lepore & Helgeson, 1988). Essentially, these findings support the social-cognitive processing view of adjustment which frames prostate cancer diagnosis as a traumatic

experience that patients have to actively process in order to adjust (Lepore, 2001). It seems finding a role which provides a platform to help others can act as a way to process experiences, (reformulate views of the world) and even temporarily increase psychological wellbeing (Park, Edmondson, Fenster & Blank, 2008).

Humour was involved in participant's efforts to make a positive transition and it emerged that participants and their families used humour throughout the adjustment process to deal with challenges and positively reflect on past memories. The way in which participant's positively enacted humour exemplifies Chapple & Ziebland's (2004) extensive analysis of humour in testicular cancer patient's narratives that suggests humour has an applied use for cancer patients. In the current study, humour functioned as a method of reducing the seriousness of prostate cancer experiences and created a sense of normality in everyday life during adjustment. Whilst it has been reported that humour can facilitate communication for prostate cancer patients in support group settings (Olliffe et al., 2009) and reduce the perceived seriousness of doctor consultations (Smith, Braunack-Mayer, Wittert & Warin, 2008), limited research has investigated how humour specifically influences the adjustment process. The use of humour identified in this study seemed to serve a dual purpose for participants by conveying the importance of staying positive, whilst indirectly sharing experiences that they personally found challenging i.e. living a less active life. As understood through the theory of cognitive adaptation (Taylor, 1983) the overtone of positivity that accompanied humour use may represent how participants utilised humour as a psychological strategy to positively reframe and process experiences. Additionally, in terms of clinical implications, the secondary role of humour provides qualitative data to suggest analysis of humour may prove a

useful assessment tool to help clinicians uncover specific experiences that prostate cancer patients struggling to adjust find personally challenging (Demjen, 2016).

Methodological Considerations

Due to the qualitative approach utilised in this study, the findings are subjective in nature and based on the experiences of the participant's recruited (Biggerstaff & Thompson, 2008). IPA requires the researcher's interpretation of participant's experiences and member checking was completed with a participant group to ensure the accuracy and increase the trustworthiness of these interpretations. One anonymised transcript was discussed confidentially with the research team to provide an alternative insight into the data and increase research credibility (Morse, 2015).

Considering the researcher was male, additional barriers to communication may have arisen related to masculinity when interviewing participants about their sensitive health-related issues (Oliffe, 2010; Witty et al., 2014). The researcher was aware of this and reviewed guidance provided by Oliffe & Mróz, (2005) and attended several prostate cancer support group meetings prior to data collection to build rapport with participants which helped facilitate open communication.

The researcher aimed to provide a 'thick' description of the data collection procedures employed to increase the transferability of the research supported by a comprehensive audit trail (Tracy, 2010). However, the self-selecting nature of the sample may limit this aim as findings are transferable solely to prostate cancer patients of a similar background (Leung, 2015). Recruiting black males who as a population are reported to have a greater risk than white males of developing

prostate cancer including at a younger age may elicit new findings (Odedina et al., 2009). Similarly, while in some aspects the sample was homogenous there was variation in age, employment status (though all participants were either retired or deemed unfit to work at the time of data collection) and diagnosis in terms of disease progression which may impact upon the lived experience. Participants were recruited from a charitable support group and accordingly may represent a subsection of prostate cancer patients who were actively engaged in voluntarily roles. Nonetheless, the study findings illuminate the facilitatory benefits of adopting a voluntary prostate cancer centred role during adjustment to counteract the negativity some males can experience (Oliffe, 2009). It may, nevertheless, have been valuable to seek participants from outside the support group, as they could have had differing experiences of adjustment. Finally, given the small sample size in the current study, further research specific to adjustment would be beneficial to discover whether PCA patients of different backgrounds employ strategies such as humour in the same way to enhance adjustment.

Future research and practice implications

The current study has provided qualitative data to contribute to understanding the lived experience of adjustment to prostate cancer. There is a growing body of qualitative research addressing male's experiences of prostate cancer, however further research with an adjustment specific focus is needed to build on the current study's findings.

This study has identified that uncertainties based on bodily functions and PSA tests are common post diagnosis and can have an enduring influence on the

adjustment process and accordingly further research is needed to explore beyond the screening and diagnostic phases. Whilst masculinity has previously been associated with the prostate cancer experience, it would be beneficial for further research to investigate its influence on the adjustment process directly considering the differences found in male's constructions of masculinity. Finally, the exploration of positivity warrants further attention considering the short and long term beneficial influence both pertaining to being a 'Prostate Champion' and the influence of humour.

Conclusions

This study has explored the lived experience of the adjustment process for prostate cancer patients, a topic that has received limited direct attention. To conclude, findings revealed that the lived experience of adjustment to prostate cancer is complex and involves living with the uncertainty of prostate cancer and enduring the worry of PSA test scores. The adjustment process involved dealing with changes to perceived masculinity and to deal with the challenges prostate cancer presented, the role of a Prostate Champion and being humorous helped males in their adjustment process. Further adjustment specific research is needed to fully understand the complexities of the adjustment process to prostate cancer.

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