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This is an Author's Accepted Manuscript of an article published by Taylor & Francis in *Psychology & Health* on 15 May 2015, vol. 10 (10). pp. 1164-1182, 2015. © Taylor & Francis. Available online at:

<http://dx.doi.org/10.1080/08870446.2015.1040016>

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Men's strategies for preserving emotional well-being in advanced prostate cancer: An interpretative phenomenological analysis.

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Travel and accommodation expenses for interviews provided by Prostate Cancer UK

Note: This article may not exactly replicate the final published version:

Levy, A. & Cartwright, T. (2015). Men's strategies for preserving emotional well-being in advanced prostate cancer: An interpretative phenomenological analysis. *Psychology and Health*, 30(10):1164-82. DOI: 10.1080/08870446.2015.1040016.

<http://dx.doi.org/10.1080/08870446.2015.1040016>

ABSTRACT

Objective

This study explores men with advanced prostate cancers' own practices for promoting and maintaining emotional well-being using Interpretative Phenomenological Analysis.

Design

Five men with advanced prostate cancer participated in face-to-face, semi-structured, in-depth interviews.

Results

Within rich narratives of lost and regained well-being, two super-ordinate themes emerged – 'living with an imminent and uncertain death' and 'holding on to life.' Well-being was threatened by reduced sense of the future, isolation and uncertainty. Yet, the men pursued well-being by managing their emotions, striving for the future whilst enjoying life in the present, taking care of their families and renegotiating purpose. Running through participant's accounts was a preference for taking action and problem-solving. Sense of purpose, social connectedness and life-engagement were revealed as concepts central to improving well-being, indicating areas which practitioners could explore with men to help them re-establish personal goals and life-purpose.

Conclusions

The findings also add weight to the evidence base for the potential value of psychological interventions such as cognitive behaviour therapy and mindfulness in men with prostate cancer.

Keywords: prostate cancer, qualitative, lived experience, well-being, self-management, coping

INTRODUCTION

Prostate cancer is the most common cancer in men in the United Kingdom (Cancer Research UK, 2013a). Advanced prostate cancer has spread beyond the prostate and although incurable, can be controlled through treatment such as androgen deprivation therapy (ADT), chemotherapy, palliative radiotherapy and other palliative treatments (National Institute of Clinical Excellence, 2008). Approximately thirty per cent of men diagnosed with advanced disease will live for at least five years (Cancer Research UK, 2012). The physical morbidities of living with advanced prostate cancer include fatigue, pain and urinary difficulties caused by the spread of the disease (Thompson et al, 2007; Parsons et al, 2009; Clarke, 2006).

A diagnosis of cancer inevitably has psychological consequences (Infurna et al, 2012) and the psychosocial burden of prostate cancer is well documented (De Sousa et al, 2012; Weber & Sherwill-Navarro, 2005). Patients with advanced prostate cancer particularly experience decreases in health-related quality of life (Resnick & Penson, 2012), and consequently fare worse in terms of psychological distress and adjustment than those at the localised disease stage (Bloch et al, 2007). As well as emotional distress on receipt of diagnosis and prognosis (Jonsson et al, 2009), men with advanced prostate cancer experience on-going impairments in psychosocial functioning, for example in relation to the physical consequences of disease progression such as pain and fatigue (De Sousa et al, 2012). The limited research into psychological well-being in men with advanced prostate cancer tends to focus on the side-effects of ADT, for example clinical reports of depression and mood swings relating to testosterone depletion (Sountoulides & Rountos, 2013). Qualitative research has shown that physical side effects such as hot flushes, sexual dysfunction and breast swelling are linked to loss of identity, feminisation, feelings of self-loathing and reduced self-esteem (e.g. Ervik & Asplund, 2012; Navon & Morag, 2003; Oliffe, 2006). Living with advanced prostate cancer is

also inevitably characterised by fears over disease progression and the end of life (Penedo et al, 2013).

As well research focusing on negative psychological consequences of cancer and deficits incurred as described above, it is also important to consider positive approaches to well-being in people with cancer. Knowledge of men with prostate cancers needs and motivations has potential to inform relevant interventions (Cockle-Hearne & Faithfull, 2010). For example, self-reported stress management skills are correlated with emotional well-being in men with advanced prostate cancer (Penedo et al, 2013). The limited qualitative literature with patients with advanced prostate cancer has additionally identified some ways in which men attempt to cope with specific aspects of their illness. For example, Lindqvist et al. (2006) explored men's experiences of living with bodily changes associated with advanced disease. In particular the authors examined men's attempts to reclaim wellness, conceptualised as a physical rather than psychological state, obtained through controlling bodily problems, social comparison and obtaining medical help. Navon and Morag (2003) identified interpersonal and individual level tactics such as avoidance, self-redefining and self-soothing, used by men to mitigate the effects of hormone therapy. Although not explicitly addressing well-being, Jonsson et al, (2009) found that men newly diagnosed with advanced cancer initially limited emotional expression and withdrew socially in order to protect themselves, but participants also stated an intention to live more fully. How they would go about this was not, however, explored in any depth as this was not the focus of the study. Whilst these studies provide some insight into the ways in which men cope with difficulties and loss, there is a lack of research concentrating on positive approaches to well-being in men with advanced prostate cancer.

There are a number of lenses through which to usefully explore positive approaches to well-being in men with prostate cancer. Firstly, eudaimonic or psychological well-being is particularly pertinent given its concern with self-actualisation of human potential through

autonomy, mastery, growth, social relations, sense of purpose and self-knowledge (Deci & Ryan, 2008). Whilst, in the cancer literature this is often examined in terms of recovery from cancer (Aspinwall & MacNamara, 2005), there is less exploration of how eudaimonic well-being manifests in patients who are coping with the fact that they are dying from cancer.

Secondly, well-being can be seen as gendered in that men with cancer who espouse traditional masculine beliefs are more likely to have increased depressive symptoms (Pudrovskaya, 2010).

Masculinity plays a part in men's emotional regulation in that men are more likely than women to delay presentation of depressive symptoms until they have reached crisis point and opt for avoidance, self-reliance, social withdrawal and tough self-talk rather than help-seeking (Courtenay, 2000, Ridge et al, 2012). However current discourse in health psychology research is re-focusing on how men engage with well-being rather than merely highlighting their deficiencies (Ridge et al. 2012). For example in turning to meditation (Lomas et al, 2013) or seeking help for depression (Johnson et al, 2012).

Therefore this study aims to explore men with advanced prostate cancer's own practices for promoting and maintaining emotional well-being. Interpretative Phenomenological Analysis (IPA) was chosen as a conceptual and analytical approach given its focus on understanding how people make sense of their experiences (Smith et al, 2009). It has already been used to study the experiences of people with cancer (e.g. Appleton et al, 2013) and there has been a call for IPA to become less focused on deficit, exploring views on resilience and wellness (Reid et al, 2005). Since IPA treats participants as experiential experts, it has potential to provide access to detailed knowledge of men's own approaches to well-being whilst living with a terminal disease. Such knowledge has the potential to inform development of psychological support services that are more acceptable to men with prostate cancer (Olliffe et al, 2009), as these services are underutilised in this population (Lintz et al, 2003; Weinberger

et al, 2011). Therefore a key research question in this study is: how do men with advanced cancer promote and maintain their emotional well-being?

METHOD

This study is a qualitative design utilising face-to-face, semi-structured, in depth interviews and Interpretative Phenomenological Analysis (IPA) (Smith, 1996). IPA is phenomenological in that it is not concerned with forming objective accounts of events, but instead focuses on the subjective reports of the individual (Brocki & Wearden, 2006). IPA involves detailed examination of participant's experiences - whilst one does not have direct access to them, attempts are made to get as close as possible, through focus on idiographic case studies using small purposive samples (Smith, 2011; Smith et al, 2009). This requires awareness of and reflection on 'the double hermeneutic' where the researcher is positioned as 'trying to make sense of the participant, trying to make sense of what is happening to them' (Smith, 2011, p. 10).

Participants

Participants were recruited by the researcher from Prostate Cancer UK's (a registered charity) pool of volunteers. Selection criteria stipulated that participants were English speaking men with advanced prostate cancer, who self-identified as using strategies to maintain their emotional well-being. An advert was placed in a bulletin received by volunteers as part of their communications with Prostate Cancer UK. Men who came forward were contacted by telephone or email by the researcher and asked to confirm basic details (as per inclusion criteria above). A purposive sample of five participants was recruited – this is consistent with IPA guidelines of sampling to allow the rich interpretation of each case (Smith et al, 2009). Participants were living in North-West, South-West, South-East England and London, they were all white and were management level professionals, who had either retired or taken early

retirement due to their diagnosis. Four of the participants were married and one was in a long-term relationship; they all had children. See Table 1 for participant details.

Data collection

A semi-structured interview schedule using open-ended questions was developed by narrowing down from the broad research question to a range of topic areas, bearing in mind sequencing and possible phrasing of questions (Smith et al, 2009). Participants were initially asked to talk through their diagnosis and treatment; further questioning covered personal meanings of well-being and emotions, the impact of prostate cancer on well-being, and strategies used to keep emotionally well. In practice the schedule was used purely as a flexible guide, the interview narrative was driven by the interviewee (Smith, Flowers & Larkin, 2009). Participants were interviewed by the first author in their own homes. Interview duration was between 1 hr 27 minutes and 2 hrs (M time = 1 hr 45 minutes). These were recorded, transcribed verbatim with pseudonyms given to participants in order to preserve anonymity. A research information sheet was provided to all participants and consent was obtained before each interview. Debriefing involved ascertaining whether any difficult issues had arisen with details of relevant organisations to hand if necessary. Ethical approval was obtained from the University of Westminster research ethics committee.

Data analysis

Interview transcripts were analysed using the procedure detailed by Smith et al. (2009). This involved case by case repeated re-reading and re-listening to ensure full immersion in the data; followed by close notation comprising descriptive, linguistic and conceptual observations made in order to produce an initial detailed analysis of each transcript. Emergent themes were then developed from initial detailed notes, connections across emergent themes were explored and drawn together to form super-ordinate themes. Once all cases were

analysed separately, they were analysed collectively. Patterns were identified, to produce a final model of cross-cutting super-ordinate themes, accounting for similarities and differences across cases (Smith et al, 2009).

Evaluation of the value of IPA research has resulted in clearer parameters for quality, which include ensuring the analysis is interpretative, but also involves consideration of reflexivity (Brocki & Wearden, 2006; Smith, 2011). Therefore the researcher made reflective notes after each interview, kept a reflective journal and discussed emotional and analytic reactions with the co-author. Whilst the first author's role as an information professional at Prostate Cancer UK, brought benefits such as an existing knowledge, there were also tensions, including a disparity between her role as an information professional at Prostate Cancer UK who provided support and maintained relationships with clients, and as a more emotionally distanced researcher. This divorcing of identities is noted in other studies in which nurses, therapists and other health and social care become researchers (Dowling, 2006). Awareness of her role in the interpretation meant that the original interview transcripts were repeatedly returned to in order to check against the participant's original accounts, grounding interpretation in excerpts and evidencing convergence and divergence between experiences (Smith, 2011). Individual transcripts and analytic processes and emerging themes were also discussed with the co-author – a researcher specialising in long-term conditions and qualitative research - as triangulation is an important aspect of rigour in qualitative research (Owens & Payne, 1999).

RESULTS

The interviews provided detailed accounts of diagnosis, treatment and the physical and emotional impact of cancer in terms of dealing with changed bodies, fatigue, pain and low mood; as well as positive and negative experiences of the health system and help-seeking for emotional distress. However, the focus of this paper is on two super-ordinate themes that

emerged from participant's accounts – 'living with an imminent but uncertain death' and 'holding on to life.' This notion of living with death emerged as a key thread through all participants' accounts and is strongly supported by significant evidence within the transcripts. Additionally, the focus on two key themes enabled the depth of analysis and reporting central to an IPA approach.

Living with an imminent but uncertain death

The impact of living with death as an imminent reality on emotional well-being emerged as an unprompted theme during all the interviews, with some participants dwelling on it more than others.

Temporality and the future self

The men's accounts pointed to the disrupting nature of the cancer diagnosis. The expected trajectory of their life events was interrupted, and the men were more aware of time passing. In addition, for some of the men the wearing away of their future identity led them to question their previous choices, actions and identities, as Robert exemplifies with a sense of disbelief: 'but it still stuck with me - ah you won't reach retirement age. What? I thought I was going to do all these things when I was retired, because I was working incredibly hard.'

The men were unable to completely focus on the transient and sometimes uncomfortable nature of the present, whilst also having difficulty in planning for an uncertain future, creating internal conflict and challenging their identities, which were often bound up within their familial role. For example Mick often referred to a future in which he was no longer present by highlighting everyday frustrations of being unable to make future commitments to his family, such as taking his daughter to the Olympics: 'I kept saying to her, I can't promise because I don't know that I'm going to be here, but I promise if I'm here we'll go.' More

broadly, this challenged Mick's sense of self as a protector of his family – so again, lack of sense of a future had ramifications for his identity in the present.

Uncertainty and loss of control

Cancer emerged in the accounts as a source of embodied uncertainty, as well as an external force that has infiltrated the men - an 'it' causing irrevocable harm pre-diagnosis: 'certainly, until I had the treatment it was obviously doing a great deal of damage' (David). Alongside an on-going lack of control over their bodies, participants had to live with side effects like pain, fatigue and rising prostate-specific antigen levels. Robert conveys a sense of watching and waiting through vigilance to symptoms as signs of impending death, which he described through metaphor – representing feelings of fear, dread and heightened anticipation:

Day to day the thing that bother me most and I describe it as creaking floorboards, you know when you're in on your own and you hear the floorboard creaking and you think is somebody upstairs? And you're quite scared by it. I get numerous little pains here and everywhere, particularly round the groins, you think – is this it now? Is this it? It sounds so dramatic – **is this it?** But is this it, is this it now? Here we go. And that sets - oh I get scared sometimes where I think, it's like a little unexploded bomb isn't it?

(Robert)

Four of the participants were given limited but vague prognoses, which meant they remained uncertain about how much time they had remaining. The cancerous body is no longer a certain body, and is described in other metaphors to convey the men's lack of control – there is a sense of the momentum of rolling forward uncontrollably into an undesirable future. For Jack, living with this uncertainty triggered a period of low mood, when he was anticipating and waiting for a decline, with no way of predicting when this might occur: 'I was thinking –

any time now, I'm gonna start going downhill.' In some respects Mick had more certainty over the time he had left, having recently been told that he might only have weeks or months left to live. However his use of the word *might* highlights the ongoing uncertainty together with fears around the unknown nature of death as illustrated in his analogy:

I suppose that I likened it to y'know perhaps driving down one of those Italian mountains in a car with no brakes, you're steering and you don't know where the car's going to go and you can't stop it, and you can't wait for the bottom of the mountain to come to try and slow the car down sort of thing, if you get there at all. (Mick)

Separation from life

As men with advanced cancer living with disrupted life trajectories they narrated accounts of being alive, but with imminent death creating a shadow over their present self and separating them from the world of the living. For some, this was most salient in terms of their social roles, so for example Clive fears giving up work as 'I worried that you know I'd be at home a lot on my own, and would that, psychologically, would I you know vegetate almost?' Use of the word *vegetate* communicates underlying feelings of decay and loss, connecting to Mick's account which conjures-up an image of darkness and death closing in as life recedes:

You can sort of almost feel your life shutting down, because the window of time that you are actually awake is shortening, um, which again is something that is difficult to deal with, um and difficult to cope with, y'know emotionally.

The gradual physical destruction of the body and lack of connection to others seemed to relate to feelings of existential terror and a questioning of the significance of their lives particularly exemplified by Robert's reflection on his panic attacks:

I started to think, hang on what are these things, what am I panicking about?
And to me, the more I think about it is, uhh in the big picture, actually
nobody does care. I'll die and be buried and burnt or whatever – who cares?
And, quite interesting nihilism viewpoint. But all of a sudden I thought – oh
my god – that is actually quite true – nobody cares?

Holding on to life

In order to respond to the biographical disruption of a diagnosis of advanced prostate cancer and the uncomfortable notion of their own imminent but uncertain death the men responded by 'mobilisation of resources' (Bury, 1982) maximising potentially positive outcomes, whilst also holding on to hope for the future (Williams, 2000). These strategies ranged from more consciously devised and active methods, to less conscious approaches and attitudes conveyed through the narration of their experiences. Within each sub-theme there was inevitable variation between participants – since well-being is personal and individual.

Containing and revealing emotions

Interviewees accounts sometimes displayed a tension between expression and control of emotions in response to their situation, which seems to reflect a struggle to adhere to and re-evaluate masculine identity. All the men sought ways to express feelings to people outside of their family, such as keyworkers, cancer peers and counsellors: “like talking to you now, it was great to put things in context and talk to someone who wasn't connected” (Robert). At the same time as valuing emotional expression as therapeutic, participants also revealed a need to display emotional strength in order to protect themselves and in some cases their family. For example, creating psychological distance from death and reinforcing their vitality and 'aliveness' thereby confirming their masculine sense of self. Jack asserted a position of ignoring

death, 'I suppose some people think well, erm, I'm gonna die, you know? How do I feel about death? I don't think like that, I've never really thought like that.' Similarly, Clive created distance from death through euphemistic language such as 'longevity,' 'latter stages' and 'end of the journey.'

In keeping with a traditional masculine attitude some participants created a distance from emotions themselves, for example Mick views 'feeling down' as a weakness that should be challenged, Robert states that he is 'not just a sort of feeling person,' preferring to rationalise and take control of emotions by 'giving himself a good talking to':

There's no point in moping about, there's no point in getting worked up about it. The way I deal with it is saying right, that's the way things are.

However, at times there was a sense that this strong stance against emotions was a struggle, and they could not suppress their distress. They were instead able to also re-appropriate expression of emotion as a sign of bravery: 'it's not a word that I'm afraid of, it's a word that I understand. I know that I have emotions' (David). Jack, Robert and Clive also expressed a changed emotionality, in particular increased crying, which they linked to the effects of androgen deprivation therapy. Crying becomes an action with a purpose – for Robert and Clive it allowed a deeper experience of music and films and increased emotional connectivity. Jack is defiant in the face of opinion that crying goes against masculine norms, repositioning crying as purposeful action aimed at gaining relief:

The emotion that comes out when you have a good cry, and I'm not afraid to say so. I don't care, if I cry, I cry. You know, men aren't supposed to cry,

nonsense, absolute nonsense, it's the biggest relief of the lot. Have a good boo!

Striving towards the future

In response to living in a limbo state in which they found it hard to be in the present or plan for the future, four of the participants strove to move forward and survive in an active and goal-orientated way. There was a sense of taking hold of time and managing it, for example Mick's use of the phrase '*stepping stones*' conceptualises how his daily, weekly and monthly goals acted as bridges between time: 'it just gives you the stepping stones of targets and goals and achievement, to look forward to.'

There was a sense of wilfulness and optimistic perseverance in their strategies, for example Mick committed plans to calendars and diaries, creating a sense of permanence in the face of impermanence. David used assertive self-talk: 'I plan to live 20 years, so I'm just going to carry on as if I am going to live 20 years.' Similarly, Jack employed the same forward-focused narrative to affirm his continued survival: 'now it's a case of we've got 3 holidays booked for this year. And we wanted to go to Italy, so we booked it for next year. I'm going, you know, **I'm going.**'

In particular, this sense of wilful activity often emphasises physical strength and the ability to control their thoughts about the future, and more broadly fight the disease. For example, Mick has limited physical movement, but maintained his drive through the psychological process of 'fighting' itself, 'there's certain things that I can't do and I just have to accept that, but what I can do, I do and fight to do.' (Mick)

Thus reinforcing masculine identity in face of an illness which in some respects has stripped them of their power and control:

I'm probably physically stronger than most people who've got this disease.

So I am that average person or I am the high end of average? And I just keep thinking well: I'll be the high end of average. (Clive)

The men also persevered by gathering information about potential medical interventions available should their current treatment become ineffective, which seemed to spur them on physically as well as psychologically: 'and you just think well – this drug is coming, so as long as I can keep going...as long as I can keep physically trying to keep myself in better shape, you know some...something will come along.' (Clive)

Living in the now

In contrast, at times the men also moved out of the unstable state between life and death, by being more present through leisure pursuits, hobbies, socialising and family time. For some this was through activities that emphasised mindful awareness and sensory pleasure in the moment, whilst also reinforcing their sense of self and remaining physical ability through existing hobbies. For example, Robert was already a keen surfer and David a regular gardener:

Getting out into the physical world, going on the beach for surf. Solitary, on my own, astride a surfboard, all these beautiful natural forms and shapes and smells and sounds around you. And it just puts you in a ...I don't want to sound a bit too stupid...but you know a transcendent state. (Robert)

I can just walk round the garden and just see, this is coming out, that is coming out, what am I going to do with this next year, this has not worked, this is dull, y'know what am I going plant here? Y'know it makes me happy. (David)

As well as reinforcing his remaining bodily wellness and sense of coherent self, Robert's gardening allowed him to appreciate the present and make plans for the future of the garden - something which will endure after his death. Clive's hobby of singing in a choir gives him access to the hedonistic highs of performing on television and in concert halls and the sensory joy of really being alive and fully committing to experiences. In contrast to Robert and David's established hobbies, Clive's uptake of a new activity can be seen as an attempt to reconstruct his identity in the face of the disruption to his life that cancer has brought. This highlights a drive to follow his passions, with a present and sensory focus, rather than being concerned with the outside world i.e. the fact that he can't sing:

I love music...it's one of my absolute passions, and it's why I said I'd go along. But I'd never been a great singer. My wife would tell you I can just about carry a tune, but I'll belt it out now.

Taking care of the family

Four of the participants used normalisation as a strategy in the face of the psychological turmoil caused by advanced cancer and facing death, they worked to protect their identities as family men – fathers and partners with a duty to look after their loved ones. For four of the participants this was achieved through taking control of communication about their cancer and the prospect of their death with their families. One facet of this was making financial and practical plans around death, for example Clive mentioned sorting out inheritance with his children, Mick attempted to communicate his restricted remaining time to his daughters, and Jack asserted control over his fears about a future in which he is absent and his wife is alone by making careful plans. By channelling thoughts of their own death towards their family's future well-being, the men were able to maintain their role as head of the family even after their death, thereby enhancing this role in the present. This is exemplified in Jack's

description of the importance of an active-coping approach in which he deals with problems head-on:

I've basically said I'm not going to put my head under the pillow and just let things happen. We've subsequently currently sorted our wills out, our executor knows everything that he needs to know, they've got keys...it's all...oh I've got a funeral plan. All of that has been done. And erm, I think because we've done all that, that's helped me to deal with it. Because I know that my wife's going to be ok.

Robert's communication with his family focused more on conveying his wishes about death. Humour served as a mechanism for tackling this important but sensitive topic with his family, whilst shielding them from the full-force of it. Again, Robert takes control and emphasises his enduring identity within the family, by rejecting the traditional paraphernalia of death, the 'stinking' hearse, in favour of the family car, and positioned himself within the family, even after his death:

I said the other thing I don't want is, I don't want a hearse, I'm not having a stinking hearse...I said in fact I want that car, put the front seats down, and where we normally put the tandem, put the wicker basket and I want to go in that. And she said I don't want to do all that...and I said...I'm not having a hearse, and we were laughing and joking about it.

David also preserves a sense of control, but through withholding information, both to protect his family and to assert power as the one managing the illness, helping to maintain a sense of self - a person used to being in charge:

So I tend to not say everything I tend to sort of drip feed it to a certain extent.

I've got a son and certainly when my PSA started to go up, I didn't tell, I

haven't told him that, because I take the view, there's no point in him worrying, you can't do anything, you'll only worry, you'll only be upset, so I'm not going to talk to you about it.

Renegotiating purpose

Having a purpose through employment was an important facet of all of the participant's pre-illness sense of self. Yet their diagnosis of advanced cancer meant they all had to give up their employment and risked losing their sense of purpose. However, all participants had renegotiated their sense of who they were through meaningful activity. Even though they are living with the fear of limited lifespan, they reassessed their new lives as having more meaning and vitality: 'I've been given the chance to live my life to the full' (Jack).

The benefits of new activities like volunteering were multi-faceted, they enabled the men to achieve a sense of belonging in the world, and social connection to counteract the feelings of separation that their 'between life and death' state entailed: "you feel wanted, you're putting something back" (Jack). In particular the previous level of importance or difference they made at work or in social activities is evoked through new roles. For example, Clive emphasises how his new volunteering role will involve meetings with the chief executive and financial executives of a charity, Robert, an ex-teacher has a sense of continuity through his new role in educating people about prostate cancer:

There was a lady who said to me, why don't they just take men's prostates out, why don't they take them out? So I explained and she said, well I never knew that, and then I thought, well that's helped.

DISCUSSION

This study enhances knowledge about the impact of living with advanced prostate cancer and

the threat to well-being of facing an imminent but uncertain death. It adds to the existing literature through its focus on those living at home with advanced cancer. In contrast previous studies have tended to concentrate on hospice settings without taking into account those who may be living for years with the knowledge of their terminal prognosis (Nissim et al, 2012). The findings provide novel insight into how those with terminal illness work to manage the tension between appreciating life in the present whilst thinking about the future, through goal-setting and optimistic perseverance. Additionally, the findings provide a more nuanced picture of men's emotional responses to cancer diagnosis and prognosis, such as their drive to manage emotions and problem solve, whilst also expressing distress and seeking help. Participants pursued well-being through renewing their life purpose, strengthening social connectedness and seeking absorption in mindful activity, which suggests that a eudaimonic approach to well-being for men with advanced cancer could be investigated further.

Specific themes found in other research are echoed here, including lack of control over bodies (Chapple & Ziebland, 2002; Kelly, 2008), bodily changes as warnings of impending death (Lindqvist et al, 2008; Sand et al, 2009), uncertainty and unknowing during the palliative care stage (Nissim, et al, 2012), feelings of social separation (Koffman et al, 2012) and existential loneliness (Strang & Sand, 2006). Similarly, other research has found that cancer survivors and those living with advanced cancer show an increased awareness of time, difficulty in reflecting on future time and sense of a receding future (Cecil et al, 2010; Lindqvist et al, 2008; Rasmussen & Elverdam, 2007). Of particular importance is the notion of 'liminality' (Little et al, 1998) which conceptualises a state in which people have been declassified without being reclassified, or trapped between culturally established categories (Navon & Morage, 2004, p. 2338). It was initially identified by Little et al (1998) as a concept to express the existential distress, uncertainty, chaos and limited freedom expressed by cancer patients. The role of liminality was also explored by Navon & Morag (2004) in men with prostate

cancer where hormone therapy resulted in a simultaneous normalisation and deviantisation of their lives, emotions and bodies, leaving them in a state where ‘a man is not a man’ (Navon & Morag, 2004, p 2343). In this study, the men are in a liminal state between life and death, and a desire to be in the present and exist in the future. However, this study adds greater knowledge about the tension between living in the now and striving for survival and adds insight into how men manage this uncomfortable cognition.

According to Bury (1982), biographical disruption as a result of illness necessitates a response in the form of mobilisation of resources, here strategies such as goal-setting represent a connection to the future and a way for the men to preserve emotional well-being by maintaining hope. Nissim et al.’s (2012) longitudinal, qualitative research also showed that patients with advanced cancer set themselves goals, enhancing fulfilment during the time they had left. The authors note the conservative nature of some of these goals, echoing the use of short-term goals as stepping stones to the future as utilised by some of our participants. The present study provides further detail of the experience of goal setting that may be of practical use for health professionals. For example the importance of noting down goals in a diary to create a sense of permanence and the use of assertive self-talk to affirm feelings of continued survival.

A thread through the discussions of goal setting was optimistic perseverance. It may be necessary to approach the presentation of positivity and optimism with caution. Feelings of hope and optimism linked to fighting, determination and endurance are also recounted in other studies (Jonson et al, 2009; Lindqvist et al, 2006; Oliffe, 2006), but are these men simply ‘rehearsing dominant masculinities?’ (Ridge et al, 2011). There is a popular attitude that cancer patients should battle their illness (Seale, 2002) and hegemonic masculine norms dictate that there may be even more pressure for men to adopt an aggressive yet positive stance towards cancer (Cecil et al, 2010). Wilkinson and Kitinger (2000) argue that when

discursively analysed, self-reported 'positive thinking' in cancer patients may be associated more with external societal demand to fight their illness rather than their genuine approach. Nevertheless, this study showed that for the participants, optimism equated to a physical and emotional drive for life, again allowing for hope, which is linked to increased quality of life in palliative cancer patients (Feuz, 2012).

Research into the emotional impact of prostate cancer tends to find that men are stoical and strive to suppress emotions (e.g. Burns & Mahalik, 2007; Chapple & Ziebland, 2002; Wall & Kristjanson, 2005). There was some evidence of this from participants, for example through distancing from the emotional impact of thoughts of death and a desire to assert emotional strength. However they also expressed fears, reported the therapeutic nature of increased emotionality and sometimes spoke to counsellors, key workers and cancer peers about emotional difficulties. This more complex picture of responses to emotional distress is in keeping with recent alternatives to dominant masculine discourses on health. For example research highlighting openness, help-seeking, management of distress, and a nuanced linguistic expression of emotion in some men whilst still recounting a struggle to conform to or renegotiate hegemonic masculine norms around response to emotional and physical health difficulties (Emslie et al, 2006; Johnson et al, 2012; Lomas et al, 2013; Lomas et al, 2014; Seake & Charteris-Black, 2009). It may be that the biographical disruption caused by illness, allowed the men in this study to explore different emotional repertoires (Seale & Charteris-Black, 2009), whilst also seeking to confirm their masculinity identity and vitality through managing their emotions and taking an active, wilful approach to changes in their circumstances and sense of self.

Crying is typically perceived as a feminine tendency (Peter et al, 2001), however amongst these men crying was acknowledged as non-masculine but accepted through reappraisal as an active approach with a purpose, namely to release unwanted emotions. A desire to take action

is positioned as a masculine approach to emotional difficulties or ill-health (Helgeson & Lepore, 2004; Johnson et al, 2012; Robertson, 2007) and the participants also strove towards action in other ways, by seeking solutions or problem-solving. Other studies of coping in men with prostate cancer often focus on the negative impact of a 'masculine approach' to dealing with the psychological impact of cancer, for example reduced processing and expression of cancer-related emotions (Hoyt, 2009; Hoyt et al, 2013). In contrast, the present study suggests that the impact of masculine coping styles may not necessarily be negative. By taking action the men were able to gain control of chaotic experiences and re-confirm or renegotiate aspects of their disrupted identities for example by putting their affairs in order or seeking out new activities to occupy their time, thus enhancing well-being through both the problem-solving process and the new activities themselves.

This re-negotiation of purpose through activity is in keeping with the premise that men are often defined by what they do, particularly by their employment (Robertson, 2007). Cecil et al. (2010) reported that men with cancer felt useless due to loss of work, but they did not recount attempts at renegotiated function, whereas the men in the present study actively strove for fulfilment through meaningful activities. Drawing on Park and Folkman's (1996) framework of meaning-focused coping it appears that the men in this study have moved towards adjustment through accommodating threats to life's purpose by altering their global goals and beliefs - focusing their goals and beliefs on volunteering or their family rather than employment. Substituting paid work for activities like volunteering also gave some of the men a way to preserve aspects of their professional identity and retain a coherent sense of self. Such maintenance of sense of self has found to be important in other studies of people with advanced cancer (e.g. Lethborg et al, 2012).

Purpose in life is a central tenant of eudaimonia (Ryff & Singer, 2008), so whereas aspects of hedonic well-being may be reduced for these men in terms of reported low mood, pain and

fatigue, their eudaimonic well-being is maintained and even enhanced through pursuit of meaning and purpose via activities described above. The participants were all married or in long-term relationships, which has been shown to positively influence quality of life in men with prostate cancer (Gore et al, 2005). Additionally, positive relations with others are also key aspects of eudaimonic well-being which participants maintained through taking care of their family and involvement in wider social networks. Pursuit of social connectedness also relates to the concept of ‘mortality salience’ intrinsic to terror management theory (TMT) (Greenberg et al, 1997). TMT would construct the men’s’ enhanced desire to connect with their social groups as a way to reduce death-anxiety by confirming that their values will be continued after death, as also seen in patients surviving cancer (Little & Sayers, 2004).

The relevance of eudaimonic routes to well-being are highlighted in some of the participant’s pursuit of absorption in activities. For example, through transcendent but mindful engagement with nature, physical activity, music and gardening. These activities enabled some respite from inner thoughts, directing attention towards life as it is happening. The physicality of the activities chosen by some of the participants fit with Csikszentmihali’s ‘flow theory of wellbeing’ (1990) which explores achievement of well-being through absorption in engaging, challenging but achievable activities which results in the mental state of ‘flow’ (Henry, 2006). This echoes other research in which patients with advanced cancer express a joyful appreciation for life in the present (e.g. Jonsson et al, 2009; Koffman et al, 2012, Lin & Bauer-Wu, 2003), but goes further in providing detail of the function of living in the now, such as a offering a chance to feel really alive and well in their bodies, and as a way of appreciating the present whilst also enhancing a feeling of life continuing, for example through gardening.

The study is limited by the fact that it provides a snap-shot of the interpreted experiences of only these five men, living in the United Kingdom. The sample were all white, married or in

relationships, not economically disadvantaged and of a younger age range than is typically representative of prostate cancer, as most cases are diagnosed in men aged over 65 (Cancer Research UK, 2013). This is relevant in that differences have been found in coping styles between older and younger men with prostate cancer (Roesch et al, 2005), based on income, education levels and ethnicity (Kinsinger et al, 2006) and quality of life may be influenced by relationships status (Gore et al, 2005). There is a sampling bias inherent in the fact that participants were self-selected as using coping strategies to maintain their emotional well-being and were also recruited from a pool of charity volunteers. It was not therefore surprising that activities like volunteering are important for them. However, this homogenous sample is appropriate for idiographic analysis and IPA research, which calls for small sample sizes of similar populations in order to explore lived experiences in depth (Smith et al, 2009). Further studies involving broader samples of men with advanced cancer are warranted.

Whilst, it may not be possible to extrapolate findings to all men with advanced prostate cancer, the study has value in that it has illuminated potential avenues for further research and practice. For example the men's preference for solution focused coping and goal-setting points to the relevance of cognitive behavioural therapy-type interventions. These already have some evidence base in prostate cancer support (Chambers et al, 2011). Positive psychological interventions, such as mindfulness approaches, have the potential to enhance attempts to appreciate life in the present whilst offering resolution over struggles with the future, with recent research pointing to their effectiveness in this patient group (Chambers et al, 2012). Current guidance focuses only on screening for psychological distress in this population (NICE, 2004). However, exploring a eudaimonic approach to assess the emotional well-being of men with advanced prostate cancer could ensure that issues such as sense of purpose and social connectedness are not overlooked. In general, health professionals could encourage men to explore their own resilience and coping strategies and help them re-

interpret purpose, for example through new activities that will be personally meaningful (Nissim et al, 2012).

CONCLUSION

This study provides new and in-depth information about the well-being enhancing strategies used by men with advanced prostate cancer, a previously understudied topic and population.

This research reveals that living with the knowledge of one's imminent death creates emotional distress, crisis over identity, meaning and purpose which can be on-going and intrusive. The men displayed resilience and the findings add new insight into patterns of coping strategies used to deal with these threats. Harnessing the type of active strategies and holistic sense of well-being discussed here means psychosocial interventions and services could be more appealing and therefore better accessed by men, leading to greater enhancements in their quality of life.

ACKNOWLEDGEMENTS:

The authors acknowledge the support of Prostate Cancer UK in recruiting participants and covering travel expenses. We'd also like to thank the volunteers involved in the research.

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Table 1 Participant details

	Age	Time since diagnosis	Treatments received	Physical function
David	64	4 years	Radiotherapy, androgen deprivation therapy.	Active and mobile, for example able to exercise.
Mick	50	6 years	Androgen deprivation therapy, chemotherapy, steroids, other palliative treatments.	Severely reduced physical function, unable to walk unaided and mostly confined to this chair.
Robert	52	3 years	Radiotherapy, androgen deprivation therapy.	Active and mobile.
Jack	72	10 years	Androgen deprivation therapy.	Reduced physical function, unable to exercise.
Clive	53	4 years	Androgen deprivation therapy, chemotherapy, second-line androgen deprivation therapy.	Active and mobile.