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An Exploratory Study into the Traumatic Impact of Advanced Cancer among Patients and Partners[1]

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Abstract: People living with cancer may experience both psychological distress and a sense of personal development. These two responses can be conceptualised using theories of post-traumatic stress (PTS) and post-traumatic growth (PTG), respectively. This hospice-based study investigated the range of experiences of people living with advanced cancer and of their partners, with consideration of how theories of PTS and PTG resonated with their accounts. Strategic sampling (n=11) was used to gather data from eight individuals living with advanced cancer and from three individuals caring for someone with the diagnosis. Q methodology was used to investigate the participants' subjective experiences. A set of 62 statements, informed by theories of trauma, were sorted by the participants according to the extent to which the individual statements were consistent with their personal experiences of living with cancer. The participants were then interviewed about their Q sorts, to consider the personal meanings that had informed their statement rankings. The Q sort data were factor analysed, and theories of PTS and PTG were used to aid the interpretation of four differing viewpoints: "Accepting and Growing," "Fearful yet Adapting," "Resigned and Grieving" and "Traumatised." These different expressions of the positive and negative feelings associated with living with advanced cancer are considered in relation to professional healthcare provision. The study recommends that future research involve a broader sample of individuals, including patients not accessing hospice care, the partners of this population and cancer healthcare professionals.

Keywords: Adult, advanced cancer, partner, post-traumatic stress, post-traumatic growth, Q methodology

Introduction

The psychological impact of advanced cancer: traumatic stress and growth

Approximately two and a half million people in the UK are living with a diagnosis of cancer. The figure is projected to rise to four million by 2030 (Maddams, Utley & Moller, 2012). Due to medical advances, the number of individuals living longer after a diagnosis of both early stage and advanced cancer is increasing (Low, Beram & Stanton,

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2007; Maddams et al., 2012). The financial cost to society has been estimated at more than £15 billion per annum, including healthcare costs of £5 billion (Department of Health, 2013; Featherstone & Whitman, 2010; Marti et al., 2016). At an individual level, cancer can have a detrimental impact on psychological, physical and interpersonal wellbeing (Brennan, 2004).

People with a diagnosis of advanced cancer live with the knowledge that their illness is incurable, as it has either metastasised, spreading from its original location to secondary sites (Low et al., 2007), or is based in one location but not amenable to curative treatment (American Cancer Society, 2014). For such individuals, time is precious, and healthcare professionals are urged to provide high-quality holistic care (National Institute for Clinical Excellence, 2004; Marti et al., 2016), which should involve regular "discussion of patients' needs for physical, psychological, social, spiritual, and financial support" (National Institute of Clinical Excellence, 2004 p. 7). Whilst psychological intervention is as important as other forms of intervention (Department of Health, 2007), the provision of psychological support is limited (National Institute of Clinical Excellence, 2004). In the absence of effective curative treatment, focusing on ensuring a good quality of life is fundamental to palliative care (Greisinger, Lorimor, Aday, Winn & Baile, 1997). Healthcare professionals therefore need a sound awareness of the psychological impact of advanced cancer.

The prevalence of psychological problems among individuals living with advanced cancer is high (Irving & Lloyd-Williams, 2010; Kadan-Lottick, Vanderverker, Block, Zhang & Prigerson, 2005; van der Lee et al., 2005), with approximately 50% of this population meeting the criteria for having a psychiatric disorder (Miovic & Block, 2007). In response to their diagnosis, individuals can experience symptomatology consistent with post-traumatic stress (PTS) disorder.[2] Such symptoms can include hyperarousal and negative changes in thinking, including anger, fear or numbness. Individuals with PTS may also report disruption to their memory, such as fragmentation of memories related to the trauma or an increase in the vividness of these memories. They may re-experience trauma-related events through nightmares, intrusive memories or dissociative reactions. They may try to avoid associated thoughts and feelings or external reminders of the trauma, and they may develop negative beliefs about themselves and the world around them (American Psychiatric Association, 2013). Research studies exploring the traumatic nature of cancer have confirmed the occurrence of PTS, manifesting, for example, as cancer-related intrusions and avoidance of cancer-related stimuli (e.g., Gurevich, Devons & Rodin, 2002; Jim & Jacobson, 2008; Kangas, Henry & Bryant, 2002; Neel, 2000; Smith, Redd, Peyser & Vogl, 1999). Among individuals living with advanced cancer, high rates of PTS have been reported (e.g., Kirchheiner et al., 2014; Mystakidou et al., 2012; Posluszny, Edwards, Dew & Baum, 2011). Butler, Koopman, Classen and Spiegel (1999) found that 52% of women with metastatic breast cancer experienced PTS.

Within the PTS literature, Horowitz's (1986) Stress Response Theory has been influential. It was developed through observing individuals experiencing bereavement (Brewin & Holmes, 2003). Similarly, participants in the current study were facing either an impending bereavement or their own impending death. Horowitz's theory has been

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[2] Consistent with prior research (Brennan, 2001; Joseph & Linley, 2005) the term *post-traumatic stress* (PTS) will be used throughout this paper to describe post-traumatic stress disorder (PTSD).

used previously to help understand PTS phenomenology in individuals with cancer (Brennan, 2001). Traumatic experiences, such as cancer, were described by Horowitz (1986) as challenging an individual's mental model of the world and causing intense distress. The person may use denial and avoidance as coping mechanisms to protect them from the severity of the trauma. At the same time, an individual's innate need to reconcile their pre-existing model of the world with the trauma-related information means that processing may occur in a gradual manner. The individual may oscillate between avoidance and re-experiencing, gradually amending their mental model to incorporate the knowledge of advanced cancer. Excessive use of defences such as avoidance and numbness/denial may inhibit this process. Consequently, trauma-related information may remain in active memory and be re-experienced through nightmares, flashbacks and other PTS symptoms (Brewin & Holmes, 2003).

The impact of, and adjustment to, trauma are mediated by an individual's ability to navigate through life, which is influenced by their mental model of the world (Brennan, 2001; Horowitz, 1986; Joseph & Linley, 2005; Tedeschi & Calhoun, 2004). A mental model develops in response to the individual's life experiences. It includes beliefs and assumptions about themselves (e.g., I am in control), the world (e.g., the world is safe and just) and their goals (e.g., I will have children). Psychologically shocking events, such as a diagnosis of cancer, can challenge this mental model (Brennan, 2001), generating inner turmoil (Horowitz, 1986). However, the way in which individuals process and integrate information about the trauma into their existing model may also have positive consequences. These positive aspects have been theorised as symptoms of post-traumatic growth (PTG) (Brennan, 2001; Joseph & Linley, 2005). While numerous theories of PTG have been proposed (e.g., Janoff-Bulman, 2004; Zoellner & Maercker, 2006), the model of PTG developed by Tedeschi and Calhoun (2004) is considered the most comprehensive (Zoellner & Maercker, 2006). PTG is defined by Tedeschi and Calhoun (2004) as "positive change that occurs as a result of the struggle with highly challenging life crises" (p. 93). Tedeschi and Calhoun (2004) describe traumatic life events such as cancer as "seismic" (p. 95), in that they challenge fundamentally a person's beliefs and their mental model of the world. While individuals may experience automatic rumination regarding the trauma, using various coping strategies to reduce their distress and to disengage from their previously held beliefs and goals, they may also engage in effortful and constructive cognitive processing in order to rebuild their mental model, with positive changes in their beliefs (e.g., I am resilient), resulting potentially in modification of their personal life narrative, including enhanced life wisdom (Tedeschi & Calhoun, 2004).

Research studies have reported the presence of PTG in those living with serious medical conditions, including cancer (e.g., Barskova & Oesterreich, 2009; Hefferon, Grealy & Mutrrie, 2009; Koutrouli, Anagnostopoulos & Potamianos, 2012; Parikh et al., 2015). Consistent with theoretical models of adaptation to traumatic life events (Brennan, 2001; Joseph & Linley, 2005), individuals with advanced cancer may also report PTG (Moore et al., 2011; Mystakidou et al., 2007; Mystakidou et al., 2008). For example, in a qualitative study of experiences of advanced cancer (Lethborg, Aranda, Bloch & Kissane, 2006), participants reported an enhanced awareness of their inner strength, a greater appreciation for their remaining time, and an increased connectedness to those around them. The process of psychological growth involved in PTG includes positive changes over and above the individual's functioning prior to their experiencing the trauma. In line with Tedeschi and Calhoun (2004), this may for example be evidenced through a greater appreciation of life, more meaningful interpersonal relationships, an enhanced sense of personal strength, altered priorities and a richer existential and spiritual life.

While there has been a research focus in the psycho-oncology literature on PTS and PTG in relation to early stage cancer, there have been relatively few studies on the traumatic impact of advanced cancer (Broderick, 2015). To better understand the psychological impact of advanced cancer, the positive changes reported by individuals with a diagnosis, such as an enhanced appreciation for life, must also be considered (Low et al., 2007). Aside from those with a diagnosis, there is also evidence of PTS and PTG among partners of individuals with advanced cancer (Moore et al., 2011). For example, Butler et al. (2005) reported clinically significant levels of PTS among 34% of individuals who were caring for someone with recurrent/metastatic cancer. While advanced cancer can have a traumatic impact on the partners of those with the disease, this group of individuals has been largely understudied (Broderick, 2015). The term "partner" is used in the present study to describe a person who provides regular practical, social and emotional support to an individual living with advanced cancer; the term excludes professional caregivers.

Study rationale and aims

Studies have suggested that PTS and PTG are important aspects of how people respond to advanced cancer (Butler et al., 1999; Meisel et al., 2012; Lethborg et al., 2006; Mystakidou et al., 2007). PTS can impact a patient's quality of life (Meisel et al., 2012), level of suicidality (Spencer, Nilsson, Wright, Piri & Prigerson, 2010) and his or her willingness to engage in treatment (Udo & Gash, 2012). PTG serves a protective function at a physiological level (Diaz, Aldridge-Gerry & Spiegel, 2014) and is also related to enhanced quality of life (Tomich & Helgeson, 2004). Research on PTS and PTG in persons with advanced cancer is therefore potentially valuable. For example, the findings may help professionals to deliver more effective interventions to promote and maintain quality of life and psychological wellbeing. However, the evidence base on the traumatic impact of advanced cancer is limited. There has been limited application of theories of PTS and PTG to the qualitative experience of advanced cancer. Most studies have been quantitative in nature. Research on individual subjective experiences and personal traumatic impact is lacking, including the impact of advanced cancer on partners of patients.

To address these limitations and to contribute to the knowledge base, the present study used a trauma theory framework (Brennan, 2001; Horowitz, 1986; Joseph & Linley, 2005; Tedeschi & Calhoun, 2004) to inform an exploratory Q methodological study of the lived experiences of people with advanced cancer and those of their partners. The study aimed firstly to explore the range of shared experiences of individuals living with advanced cancer and partners of this population. Secondly, it aimed to investigate the extent to which theories of PTS and PTG resonated with the participants' accounts of their experiences.

Methods

Q methodology

Q methodology combines both quantitative and qualitative analysis (Shabila et al., 2014), exploring the rich subjective viewpoints of participants and arranging them into shared accounts or stories (Spurgeon, Humphreys, James & Sackley, 2012). Q methodology is apt for understanding experiences of illness and healthcare (Bang, Yun, Ham, Jeon & An, 2016; Herron-Marx, Williams & Hicks, 2007; Merrick & Farrell, 2012;

Stainton Rogers, 1991), as it provides insight into "life as lived from the standpoint of the person living it" (Brown, 1996, p. 561). The Q literature includes studies in which theoretical models have been related to participants' viewpoints (e.g., Jeffares & Skelcher, 2011). There have also been studies where the participants have comprised different subgroups who have sorted the same set of items (e.g., Deignan, 2013, 2009; Webler & Tuler, 2006). Following these established precedents, this study aimed to investigate the experiences of individuals encountering advanced cancer, both as patients and as partners of patients, and to consider how their accounts might be related to theories of PTS and PTG.

Procedurally, each of the participants (the P set) individually sorted a set of statements (the Q set) which was representative of experiences relating to the impact of advanced cancer. Participants sorted these statements into a distribution of preference (their individual Q sort) by considering their level of agreement with each statement in relation to their own personal experience of cancer. Each participant was then interviewed about the meaning of their Q sort. Factor analysis was used to identify those Q-sorts that were highly correlated with one another, and relatively uncorrelated with others, grouping these Q sorts into a factor or viewpoint (Watts and Stenner, 2012). The viewpoints were interpreted using PTS/G theory, to gain insight into the variety of shared experiences.

Q set

In a Q study, the concourse, or flow of communication encompassing a topic (Brown, 1993), is examined to generate the data gathering tool (the Q set), which may typically comprise 40 to 70 statements relating to the topic under investigation (Watts and Stenner, 2012). To examine the concourse on experiences of advanced cancer, various sources were used, including published literature on PTS and PTG among persons with cancer, a four-part television documentary on living with advanced cancer (Smith, 2014), personal video accounts featured on cancer support websites from people living with a diagnosis and partners' accounts (Macmillan Cancer Support, 2014; Novartis Oncology, 2013). In addition, two experienced cancer nurses were consulted regarding their views on the experiences of those living with advanced cancer.

Content analysis was used to code and select statements from the concourse to reflect key elements of PTS and PTG theory (Elo & Kyngas, 2008). For example, the comment, "I've had pictures that relate to illness and death pop into my mind," was interpreted as an intrusive thought, which is a common symptom of PTS (Appendix 2, item 26). This process generated an initial set of 109 statements. Duplicated statements were deleted and similarly phrased statements were merged. This resulted in a balanced Q set comprising 62 statements, of which 32 reflected aspects of PTS and the negative impact of advanced cancer, while 30 reflected aspects of PTG and positive aspects of advanced cancer. A pilot Q sort was conducted, which included a healthcare professional with experience of advanced cancer. The participants were also asked to consider the coverage, clarity and heterogeneity of the statements (Paige & Morin, 2014). Five statements were subsequently amended. The final Q set consisted of 62 statements (Appendix 2), printed on randomly numbered cards.

P set

Strategic sampling was used to select participants with a diagnosis of advanced cancer and the partners of such individuals (Watts & Stenner, 2012). To ensure a clinically homogenous sample, only those living with, or a partner caring for someone with, a diagnosis of advanced cancer were recruited. Information packs were provided to approximately 200 potential participants, who were identified by healthcare professionals working in two hospices. A total of 11 participants, eight patients and three partners, were recruited.

Q sorting

Data collection occurred either in the participants' homes or in a private room on hospice/hospital premises and took on average 2 hours per participant. All data were collected by one person (Author 1). Participants were asked to sort the 62 statements into a quasi-normal distribution from most agree (+6) to most disagree (-6), with specific reference to their personal experience of either living with a diagnosis of cancer or caring for someone with cancer. The participants modelled their individual subjective viewpoints, impressing self-referential meanings onto each Q-statement (McKeown & Thomas, 1988). Participants first sorted the statements into three initial piles – "agree," "neutral" and "disagree" – to facilitate the placing of the statements along the wider continuum (Stainton Rogers, 1995). The final position of each statement in the Q-sort was recorded for subsequent data inputting and analysis. All participants engaged in an individual post-sort interview in which they were encouraged to reflect on the personal significance of the items, particularly those with which they had most agreed and most disagreed.

Data Analysis

The participants' Q sort data were analysed using PQMethod, a dedicated Q method software programme (Schmolck, 2014). Centroid factor analysis with Varimax rotation was used, the analysis being conducted multiple times; a different number of factors was extracted and rotated at each trial, with the aim of finding a solution that was both sensitive to the participants' viewpoints and statistically appropriate (Donner, 2001). As indicated by the rotated factor matrix (Appendix 1), this iterative process yielded a final three-factor solution. Each factor had two or more significant loadings ($r \leq \pm 0.33$, $p<0.01$) which together explained 46% of the overall variance. The three factors, deriving from five patients and two partners, accounted for seven of the 11 Q-sorts. Additionally, as the aim of Q methodology is to reveal the diversity of views on a topic (Kitzinger, 1987) and to permit the expression of "many voices" (Stainton Rogers, 1995, p. 183), the Q sort of P5 (a patient), which did not correlate significantly with any of the three extracted factors and therefore represented a unique, unshared viewpoint was also examined.

Ethical considerations

The study secured ethical approval from Staffordshire University, from the manager of the hospices where the data were collected, and from the NHS research ethics committee. The study complied with ethical guidelines (British Psychological Society, 2009, 2010); each participant received a study information pack, provided informed consent and was debriefed to ensure safeguarding against any detrimental impact on his or her wellbeing.

Results

Interpretation

The aim of the data analysis was to interpret a set of meaningful factors, reflecting the range of different viewpoints shared by participants. Accordingly, the correlations between all the individual Q sorts were examined, preliminary factors were extracted, and these were then rotated to achieve a clearer representation of the distinct patterns of observations (Brown, 2004; Donner, 2001). The defining Q sorts for each factor were used to create the factor arrays (Appendix 1), each of which is an "averaged" or "ideal" Q sort, representing a shared viewpoint (Donner, 2001). The factor arrays were closely examined along with the interview transcripts to provide insight into the meanings being given to the characterising statements for each viewpoint. The data were also considered in relation to PTS/G theory. This process enabled hypothesising about the stories contained within each factor to be generated and tested (Watts & Stenner, 2012), with constant comparisons being made between the factor arrays and their associated interview transcripts (Van Exel & de Graaf, 2005). An account of each factor is provided below, including relevant item rankings (e.g., 25: -3), with the representative participants' comments in italics.

Factor 1. Accepting and growing: "I don't find cancer frightening" (P10)

Factor 1 represents the shared viewpoint of three participants (P8, P9, P10), all patients with advanced cancer.

Not afraid: This viewpoint found being diagnosed with an incurable illness less distressing than did other viewpoints (54: -4), although there was nonetheless shock after receiving the news: "My first reaction was, they've got the wrong patient, they've made a mistake, and that was really quite strong. I convinced myself for two or three days that they had made a mistake" (P8). The absence of control involved in living with advanced cancer was mediated by a belief in fate: "Nobody can stop that [death] happening. Whether, whoever, how clever they are…I think if it's going to happen, it's going to happen" (P10). This viewpoint does not appear to feel in immediate danger. Life still has meaning, and the future is still important (39: -6; 46: -6).

Strength and coping: This viewpoint has developed a sense of strength while living with cancer, becoming a better person (12: +4) and believing that facing cancer means being able to face future adversity (33: +5). While this viewpoint sees medication and/or alcohol as an aid to managing feelings (34: +5), the development of coping skills has helped particularly (2: +6). Coping skills included communicating true feelings: "I seem to have lived my life not upsetting people. Now, it's you know, I may just say what I want to say really" (P10); being flexible in encountering change: "It's a case of readapting whatever happens to your body" (P8); and learning to live in the moment and to view uncertainty as inevitable: "Whether you've got cancer or not, there's always uncertainty in life. Every minute is different so I don't really think about tomorrow and I try to let go of yesterday and stay in the moment" (P8). Engaging with a spiritual dimension to life (15: +4) is also significant. For one factor member (P8), this had involved using Buddhist meditation and other strategies to ease her distress: "You put your shoulders back, tiny little smile on your face, and it's impossible to think of anything sad. And that's the way I cope with it."

A new meaning to life: This viewpoint has changed their view on the meaning of life (35: +6), having spent time evaluating what is important and letting go of the things that no longer matter (17: +4). One participant (P10) reflected on the joy she had experienced in being more open and giving: "It's nice to do things like that, that maybe before you wouldn't have done…to open up...to be able to give." This re-evaluation also includes appreciating the smaller things in life (57: +5).

Factor 2. Fearful but adapting: "How terminal is terminal?" (P2)

Factor 2 represents the shared viewpoint of two participants, one patient (P3) and one partner (P2).

The uncertainty: For this viewpoint, the worst part of the experience was finding out the cancer was incurable (54: +6). This has meant uncertainty about the time constraints on life: "You start to think how terminal is terminal, there can't be any more terminal than terminal can there?...that's when it all starts to get awful really because they just don't know" (P3).

Cognitive adaptation in the face of distress: Feelings of anxiety were reported when thinking about cancer, becoming upset and being nervous to let out emotion for fear of falling apart (37: +2; 13: +4; 43: +3). Nevertheless, feeling distressed did not mean becoming disengaged from the experience. Viewpoint 2 was not avoiding thoughts or situations related to cancer, and did not see alcohol or medication as a way to manage feelings (31: -4; 20: -4; 34: -6). Instead, attempts were being made to adapt to the situation, looking for a silver lining and believing that something good can arise from living with cancer (9: +3; 11: +4). There were cognitive efforts to reappraise the cancer as something that could be lived with and managed: "You think, right, I've got to go with it...You've got to lift yourself back up, mind, it takes weeks" (P2). This viewpoint had also rethought how life ought to be lived (52: +5): "I have changed my priorities in that...if I want something or my children want something...I will spend the money" (P3).

Stronger interpersonal relationships: This viewpoint has learned how wonderful people can be and found that the possibility of death pulls you closer to people (18: +5, 21: +6). This closeness is manifested, for example, in a new willingness to express feelings: "We always say 'I love you' on the end" (P3). Relationships have been saved and strengthened: "We were drifting apart...but I think me having the cancer has brought us a lot closer together" (P3). The cancer has enhanced the ability to relate to others (60: -5). For example, P2 became more supportive of his partner (P1), who had cancer: "You learn to be more involved in things" (P2).

Factor 3. Resigned and grieving: "It's taken so much out of the middle of my life" (P7)

Factor 3 represents the shared viewpoint of two participants, one a patient (P4), and one a partner (P7).

The cancer experience as a journey of suffering: This viewpoint certainly does not view cancer as a gift (32: -6). Waiting for test results is particularly difficult (53: +5). The distress also includes powerful memories of cancer experiences (42: +3). One participant (P7) experienced her husband's treatment as barbaric (40: +4): "It really was horrendous. Because he's very fair skinned, all his neck was like a piece of raw meat. It was dreadful...he could smell it himself." The other participant representing this viewpoint (P4) described a pervasive sense of loss: "You can remember things that you used to do...and places you used to go and that, you can't do it anymore...so you do tend to grieve for them...those are the things that you tend to, tend to leave a hole." Losing or witnessing the loss of physical functioning is very distressing (3: +5). A person's body can let them down and prevent activities once enjoyed (51: +2): "He lost his hobby [singing] when he lost his vocal chords. That was his life" (P7). For P4, managing the changes in his body was difficult: "You can't do what you want to do, when you want to do it...your body says, 'that's it you're not doing anymore thank you' and there's not a thing you can do about it. It's the total lack of control."

Acceptance and hopelessness: This viewpoint feels on edge waiting for something awful to happen (39: +4), fuelled by awareness of the impermanence of life: "It's [death] right up in the forefront now...it does make it feel a bit scary, the inevitability of [it]all...and it's getting ever closer...and I know I'm on the slippery slope because I can experience that" (P4). In some ways, this involves a positive impression that life is not simply about time spent on this planet (1: +5): "Memories are the most important thing you leave behind" (P7). This viewpoint has evaluated what is important in life (17: +4) and express acceptance: "You're dealt your hand when you're born and you live it, you live your journey and whether you die young, die old, that's the journey of your life" (P7). However, this awareness of death is also associated with feelings of hopelessness and uncertainty: "You don't know what the next week is going to bring, let alone the next two months, so everything is just in limbo" (P7). Stories of others coping with cancer have not in any way changed how the illness is viewed (44: -6). The loss of hope is intense: "It's the uncertainty…and the hope that you have, the hope that everything is going to be alright, and then for it to be dashed, and then, it's just indescribable, I mean it's a terrible thing" (P7).

Hiding sadness: For this viewpoint, the experience of cancer has been dominated by a sense of sadness (19: +6). For P7, watching her husband suffer was very distressing (19: +6): "It's horrible when somebody's ill and going through pain and tests and wondering if it's going to be bad news." There is a fear of falling apart if one's emotions were to be expressed (43: +3) and a need to hide the distress from others, using fake smiles and pretending (10: +6). The concealment of sadness may be in order to avoid burdening others: "You're fed up enough so why should you inflict your thoughts and feelings on anybody else?" (P7). Behind closed doors, the mood can be snappy and irritable (36: +4).

Viewpoint 4. Traumatised: "It really has been the silent killer" (P5)

Unlike the other viewpoints, this one was not shared, being that of a single participant (P5), a person with advanced cancer.

Distress: For P5, the experience of living with advanced cancer has been terrifying (30: +3). She reflected on feeling in constant danger: "You know, the adrenalin is always running around." This fear means that she avoids anything related to cancer, particularly on the television (31: +4). She has experienced periods in which she has felt numb (47: +3) and has doubted whether the cancer was real (62: +3). She feels very anxious on a daily basis, partly induced by intrusive memories of a seizure she had experienced, which indicated her cancer had progressed (37: +5): "I feel anxious, I get hot, palpitations and my head does hurt and…it's because I'm thinking about the seizure." The thought of leaving her family, whom she loves dearly, means that she does not perceive any positive consequences of her cancer and in no way sees it as a gift (32: -6).

Threat: For P5, the cancer treatment has been barbaric (40: +6). Hers is the only one of the four viewpoints to agree that people with cancer can feel disgusting, disfigured or defected (40: +3). The experience of cancer has impacted her identity and threatens her desire to continue: "It changes who you are. They frighten me the treatments, because they make me want to give up the fight." She perceives her cancer as deceiving, which generates anger: "I think it's fought unfairly…It's never given me any warning...It's always been ahead of us and I think that's what I felt cross about." She reflected on how all-consuming the process had been of adjusting to the knowledge that her illness was incurable: "I've been so busy thinking about dying that I've forgotten how to live."

Finding relief: Although distressed, she feels that she has learned a lot about the positive side of human nature (18: +6). She relates strongly to other people (25: -6) and feels cared for by those around her (60: -5): "My close friends have been amazing." However, P5 craves for a sense of safety and calm: "I want to feel at peace, and I haven't known that feeling in such a long time." In searching for peace, she has become more spiritual (15: +5): "I have a cross by the bed…You just hold it and it does give me a little bit of comfort." Her heightened distress and her wish for relief mean that she has become comfortable with using medication (34: +5): "Years ago I'd be like, no, I can do this, but now I'm like, give me."

Discussion

The primary aim of the study was to explore the range of experiences of individuals living with, or caring for someone with, advanced cancer. The study interpreted four viewpoints representing differing accounts of these experiences: "Accepting and Growing," "Fearful yet Adapting," "Resigned and Grieving" and "Traumatised." These interpretations support the proposal that responses and adaptation to cancer and death can vary considerably (Brennan, 2001; Hall, 2014). The secondary aim of the study was to consider the applicability of theories of PTS and PTG to the participants' experiences. The accounts provided by each viewpoint were considered in relation to theories of PTS and PTG, which were of some utility in understanding the different perspectives.

Participants representing viewpoint 1, "Accepting and Growing," appeared to experience PTG across numerous domains, with evidence of an enhanced sense of personal strength, increased spirituality (Tedeschi & Calhoun, 2004) and a new life philosophy (Joseph, 2009). A variable supporting this growth may have been the use of specific methods for managing living with cancer, such as expressing feelings, adapting to loss, and becoming more spiritual. These coping strategies are both positive and active, using personal resources to manage a crisis (Zeidner & Endler, 1996). People with cancer who adopt such coping strategies often report greater growth (Bellizzi & Blank, 2006; Kinsinger et al., 2006; Lelorain, Bonnaud-Antignac & Florin, 2010). These strategies may reduce levels of distress, allowing engagement in constructive cognitive activity to process the trauma (Brennan, 2001) and to rebuild one's belief system and mental model of the world (Tedeschi & Calhoun, 2004). Representatives of viewpoint 1 appeared to respond to the knowledge and impact of cancer in a flexible manner: "You have to readapt and not think 'oh this is the end of the world'" (P8). This suggests that their pre-existing beliefs and mental model may have been relatively flexible, which is also associated with better adjustment (Brennan, 2001).

Individuals representing Factor 2, "Fearful yet Adapting," reported being distressed about the uncertain time remaining before their own or their partner's death. Nonetheless, they have reevaluated how they wish to live life and have experienced stronger and warmer relationships, which is indicative of PTG (Tedeschi & Calhoun, 2004). A contributory factor in the development of this adaptive process may have been their cognitive efforts in processing their experiences, in that they rethought how they wished to live life and searched for positive consequences of cancer. Engaging in positive reappraisal and active cognitive processing, as with viewpoint 2, is more likely to lead to experiencing growth and finding meaning in loss (Bower, Kemeny, Taylor & Fahey, 1998; Manne et al., 2004; Sears, Stanton & Danoff-Burg, 2003; Urcuyo, Boyers, Carver & Antoni, 2005; Widows, Jacobsen, Booth-Jones & Fields, 2005). Effortful cognitive processing of trauma-related material enables the integration of trauma into one's mental model of the world, which is essential in nurturing PTG (Brennan, 2001; Joseph & Linley, 2005; Tedeschi & Calhoun, 2004). The representatives of viewpoint 2 appeared to have developed stronger existing interpersonal relationships as a response to living with cancer. Supportive social networks have been found to nurture growth (Cordova, Cunningham, Carlson & Andrykowski, 2001; Karanci & Erkam, 2007; Kinsinger et al., 2006; Weiss, 2004). Such relationships can provide an outlet for discussing the crisis and offer differing perspectives and guidance, helping to positively rebuild one's view of oneself and the world (Tedeschi & Calhoun, 2004).

The accounts of viewpoints 1 and 2 are suggestive of growth through struggling with cancer and display similarities in terms of their cognitive, emotional or behavioural adaptation in response to the illness. In particular, the accounts demonstrate how the illness has been “encapsulated,” in that it has not consumed their identity (Nerenz & Leventhal, 1983). This encapsulation helps people to continue living life with purpose and meaning, which is associated with better psychological adjustment (Brennan, 2001).

However, viewpoint 3 seems markedly less positive than viewpoints 1 and 2. The overriding theme of viewpoint 3 appears to be one of sadness, reflecting on the inevitable losses implicit in advanced cancer. This viewpoint sees cancer as providing few positive outcomes or opportunities (e.g., 11: -5 and 58: -4). The apparently limited sense of growth should not, however, be taken as an indicator of traumatic stress; indeed, this viewpoint does not report the anxiety typical of individuals who are traumatised (American Psychiatric Association, 2013). Instead, viewpoint 3 tells a story of sadness and resignation which can be understood through theories on grieving and its consequences (Kübler-Ross, 2003; Lindemann, 1944). For example, the comments of P4 are consistent with the theory of preparatory grief (Kübler-Ross, 2003), mourning for the pleasures in life that can no longer be, for the loss of physical functioning and of life opportunities (Moon, 2015). The grief expressed in the comments of P7 is that of a person observing her partner’s suffering, whose death is understood to be inevitable, preparing for the loss of a loved one in a process of anticipatory grieving (Lindemann, 1944). She is experiencing intense “indescribable” sadness, showing an enhanced concern for her husband, the dying person (Lindemann, 1944).

The sole participant representing Factor 4 provides a particularly difficult account of living with cancer, involving fear and anger, with hypervigilance and avoidance, all of which are indicative of PTS (American Psychiatric Association, 2013). Ehlers and Clark (2000) suggest that events can be traumatic if appraised in such a way that generates a sense of current threat. Consistent with this, P5 has appraised her cancer as a “silent killer” and the treatment as extremely frightening, which may have contributed to her state of fear and continual hyperarousal. Understandably, her fear means that she sometimes avoids stimuli related to cancer, such as television adverts, and has at times gone into a state of numbness. The comments of P5 and her ranking of items 31 and 37, which relate to avoidance of cancer-related material and anxiety, provide insight into the potentially traumatising nature of advanced cancer. Likewise, her response to items 3 and 40 suggest that the changes to her body resulting from cancer and its treatment were particularly traumatising, leaving her feeling anxious and under threat. She also reported excessive rumination on dying. These understandable responses (avoidance, numbing, excessive rumination) have all been reported as potentially increasing the likelihood of PTS (Brennan, 2001) and may prevent adequate processing and integration of trauma-related material (Horowitz, 1986). While Q method is not a diagnostic tool, and no diagnosis is here attempted, viewpoint 4 seemed the one most consistent with PTS. For example, participants with viewpoints 1 to 3 disagreed with more of the statements relating to PTS symptomology than did the person with viewpoint 4 (Table 1).

Table 1. Nonagreement of F1-3 with a sample of PTS-related statements

No.	Statement	F1	F2	F3	F4
24	Certain smells, sounds, or places bring painful memories rushing back to my mind.	-3	-4	-3	0
26	I’ve had pictures that relate to illness and death pop into my mind.	-2	-3	-2	+1

No.	Statement	F1	F2	F3	F4
28	Sometimes it feels like I'm reliving painful parts of the experience (e.g., diagnosis, treatment) all over again.	-4	-1	-3	0
31	I avoid things about cancer, things on the TV, in the news, and places I see as being connected to the experience.	-4	-4	-3	+4
41	I've had upsetting nightmares which have left me feeling drained.	-3	-2	-4	-3
47	I've felt numb, almost as if I was dead inside.	-1	-2	-1	+3

The participants were recruited from a hospice setting in which they were able to receive multidisciplinary care and psychological therapy. This may have helped them to manage PTS. Nonetheless, the accounts of living with advanced cancer provided by the four interpreted viewpoints may be theorised as involving a challenge to mental models or assumptions about the world. Perhaps, to that extent at least, their experiences may be deemed as traumatic. At the same time, all four viewpoints might be interpreted as expressing a fatalistic adaptation. The rankings of the consensus statements (Table 2) suggest a shared ability, albeit in varying degrees, to remain positive and to adapt in the face of adversity. In some cases, prior trauma may help in preparing to cope with future life crises (Appendix 1, item 56). For example, participant P4 (F3), who had previously lost a young son and two brothers, commented, "You tend to be quite hard, you tend to take things in your stride…it's made me become even more of a realist and I just sort of take it as it comes and take it on the nose and that's it, get on with it" (see also Meichenbaum, 1985; Janoff-Bulman, 2004).

Table 2. Consensus items

Statement	F1	F2	F3	F4
With cancer you have to learn to give up the power and to manage the uncertainty it brings. (16)	+2	+4	+2	+1
You need to look at what's important, and let go of the things that don't matter or that bother you. (17)	+4	+2	+4	+1
Cancer causes you to appreciate the small things in life; you stop and smell the roses. (57)	+5	+4	+2	+1
I've learned a lot about how wonderful people can be. (18)	+2	+5	+3	+6
I've learned to do things that help me feel better (e.g., being positive, communicating, living in the present). (2)	+6	+5	+2	+2
I can be completely preoccupied by the cancer, which makes it hard to concentrate on things. (22)	-5	-3	-1	-1
I've had upsetting nightmares which have left me feeling drained. (41)	-3	-2	-4	-3
The world has come to feel more dangerous and scary. (49)	-1	-3	-4	-3

Statement	**F1**	**F2**	**F3**	**F4**
I’ve tried to make sense of why this has happened. (29)	-4	-3	-2	-4
I look at how I’ve coped with all this and I think I’m a weak person. (50)	-5	-5	-3	-1

The participants were asked at the end of their interviews if there were any aspects of their own experience of advanced cancer that had not been covered by the Q-set. Generally, the participants reported that their Q-sorts were a largely satisfactory representation of their experiences of advanced cancer. Ten of the eleven participants did not wish to add any additional comments. However, one participant (P3, Factor 2) stated that the most difficult component of her experience had been what she described as poor NHS treatment, which was something she had felt unable to communicate through the Q-sort. Another participant (P10, Factor 1) had also reported experiencing poor NHS care, but she felt she had been able to communicate this through item 40, “The treatment is the barbaric bit.”

However, both these participants reported feeling unsafe and upset by witnessing what they reported as the care needs of others being neglected; P3 commented that, “They’d be calling, “nurse”…people would just walk past.” She herself reported being left without food or drink. These participants highlight how some symptoms of cancer-related trauma may be iatrogenic in nature, in that the system within which treatment is delivered may have acted as a traumatic stressor. The potentially traumatising impact of the healthcare environment has been discussed previously in the literature (Hall & Hall, 2013), but this concern has received limited attention in the evidence base on cancer and PTS. Multidisciplinary care teams should consider the negative implications and potential traumatising impact of failing to meet patients’ fundamental needs (Maslow, 1943).

Q methodology does not aim to generalise findings (Newman & Ramlo, 2010), but simply to establish the existence of different viewpoints on a topic (Brown, 1980). Powerful findings can therefore be obtained using a relatively small sample size (Watts and Stenner, 2012). The aim of the study was to investigate shared experiences of living with advanced cancer. The resulting four interpreted viewpoints provided coherent accounts, which were amenable to analysis using theories of PTS and PTG. No claim is made here that trauma theories offer more utility than other available theories in understanding experiences of living with cancer. Nor is it claimed that PTS and PTG commonly occur in this group. Rather, it is suggested that the study findings provide descriptive detail and prima facie evidence of both PTS and PTG.

The study provides evidence of the applicability and appropriateness of Q methodology when conducting research with this population. Indeed, in their interviews, participants reported that the Q sort process enabled sensitive discussion of emotive topics and positive reflection. For example, P8 (F1) commented that completing the Q-sort had helped her to identify the positive ways in which she had managed her cancer. This is encouraging, as helping individuals to recognise and reflect on the positive consequences of challenging life events may nurture further growth (Joseph & Linley, 2005). The accounts of the participants suggest that individuals with advanced cancer should be encouraged to use active coping strategies and to engage in effortful reflection, as these responses may nurture growth. This possibility is supported by other research (Bellizzi & Blank, 2006; Bower et al., 1998; Kinsinger et al., 2006;

Lelorain et al., 2010). In contrast, excessive rumination and avoidance of cancer-related stimuli should be discouraged, as these responses may enhance the likelihood of PTS (Brewin & Holmes, 2003; Horowitz, 1986).

Limitations of the study

The more negative consequences of living with advanced cancer may not have been explored fully in the study. The healthcare professionals recruiting the research participants were unable for ethical reasons to approach individuals who they felt might be too distressed by their cancer. One way to address this would be for future Q-methodological research to involve recruiting palliative care professionals to do Q sorts from the perspective of specific patients known to them. Asking participants to complete a Q sort based on their perception of another person's perspective is not uncommon in Q methodology (Stephenson, 1979). This would enable palliative care professionals to share their insights on the experiences of individuals living with advanced cancer who were unable to participate personally in the research.

Further investigation with participants outside of hospice settings is also recommended. Recruiting from the wider community, beyond hospice settings, and increasing the participant group size might have yielded, for example, more participants sharing the viewpoint of P5 or might have allowed the emergence of other viewpoints. A further limitation of the study was the relatively few caregivers who were recruited; only three partners opted to participate in the study. One of these, P11, did not load cleanly on any of the interpreted factors, and thus their voice was not represented in the interpretation of the viewpoints. Nonetheless, the Q sorts and comments of partners P2 and P7 highlight how caring for someone with advanced cancer can involve grief and growth. Further exploration of the views of carers is recommended as, to date, limited research has been conducted in this area.

The findings of this study suggest that living with advanced cancer, including caring for someone with the illness, can involve different and complex responses and experiences. Theories of PTS and PTG are of some use in understanding these experiences, although the diversity and complexity of the accounts may not always be explained adequately by a single theoretical model. This suggests that healthcare professionals should consider and draw on a range of psychological models (e.g., a cognitive behavioural approach) when providing social and emotional support in palliative care contexts.

Conclusion

While limitations in a study of this sort are inevitable, insights have nonetheless been gained into the various "versions of reality" (Stainton Rogers, 1991, p.127) experienced by individuals living with, or caring for someone with, advanced cancer. The study demonstrates how the knowledge of impending death can precipitate both positive and negative changes within patients and partners. It also highlights how theories of PTS and PTG are of some utility in understanding such experiences. Most importantly, the accounts highlight human resilience in the face of adversity and remind professionals to remain aware of the potential for positive change and growth among those living with advanced cancer.

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Appendices

Appendix 1: Rotated factor matrix with defining Q-sorts emboldened

Q-sort*	Factor 1	Factor 2	Factor 3
01 (Pt)	0.40	0.55	0.14
02 (Pr)	0.20	**0.47**	0.26
03 (Pt)	0.16	**0.47**	0.32
04 (Pt)	-0.11	0.12	**0.38**
05 (Pt)	0.10	0.22	0.15
06 (Pt)	0.34	0.48	0.13
07 (Pr)	0.04	0.28	**0.73**
08 (Pt)	**0.70**	0.14	-0.03
09 (Pt)	**0.58**	0.27	-0.03
10 (Pt)	**0.67**	0.25	-0.02
11 (Pr)	0.33	0.63	0.27
% var. exp.	16	15	9

Note: (Pt)=Patient; (Pr)=Partner

Participants 1 and 2 were each other's partners, as were participants 4 and 11. Participants 03, 05, 06, 07, 08, 09, 10 either did not have partners, or their partners did not wish to take part in the study.

Appendix 2: Factor Arrays

Q sort statement		F1	F2	F3	F4
1	It doesn't matter how long you're on this planet for, it's what you do and what you leave behind that's important.	+3	0	+5	+1
2	I've learned to do things that help me feel better (e.g., being positive, communicating, living in the present).	+6	+5	+2	+2
3	It's hard to watch the body change when cancer sets in.	-2	-1	+5	+4
4	Since finding out about the cancer, I've picked up new hobbies and learned new skills.	0	-1	-5	-2
5	It's best to look death in the eye and to make a plan because this gives you more power!	0	+2	+3	-1
6	I feel like I understand myself more.	+1	-2	0	-2

Q sort statement		F1	F2	F3	F4
7	Cancer enhances your awareness of your body and of your physical well-being.	+3	+1	0	0
8	Since finding out about the cancer I've taken better care of my health.	+2	0	0	+3
9	Trying to find a silver lining has made me feel better.	-1	+3	+1	+1
10	There's a lot of sadness behind my fake smiles and pretending.	-2	0	+6	+2
11	I've convinced myself that something good can come from this, and that has helped.	+1	+4	-5	-1
12	I feel that I've become a better person through this (e.g., I'm more caring, stronger, more capable, wiser).	+4	+3	+1	-1
13	I've been in the middle of doing something and then it hits me. I feel upset and it seems to come out of the blue.	-2	+4	-5	+2
14	A great day is when I've made a difference in another patient's or partner's life, by giving hope or some advice.	+3	+1	0	0
15	I have become more spiritual and this has allowed me to find peace.	+4	-2	+1	+5
16	With cancer you have to learn to give up the power and to manage the uncertainty it brings.	+2	+4	+2	+1
17	You need to look at what's important, and let go of the things that don't matter or that bother you.	+4	+2	+4	+1
18	I've learned a lot about how wonderful people can be.	+2	+5	+3	+6
19	Watching someone you love suffer, whether they're ill or not, fills you with sadness.	+1	+3	+6	0
20	I've stopped myself from thinking about cancer, about what's happened since the diagnosis, and about the future.	+1	-4	+3	0
21	The possibility of death pulls you closer to people – you feel more warmth and more trust.	-1	+6	+2	-1
22	I can be completely preoccupied by the cancer, which makes it hard to concentrate on things.	-5	-3	-1	-1
23	Guilt is something I feel, for things I should have done, and for the things I can't do.	-3	-1	+1	-5
24	Certain smells, sounds, or places bring painful memories rushing back to my mind.	-3	-4	-3	0
25	When you're going through this you just can't relate to other people and they can't relate to you.	-1	-6	+1	-6
26	I've had pictures that relate to illness and death pop into my mind.	-2	-3	-2	+1
27	There have been times when it's felt good to ignore the cancer, to not acknowledge it.	0	-2	+2	-1
28	Sometimes it feels like I'm reliving painful parts of the experience (e.g., diagnosis, treatment) all over again.	-4	-1	-3	0
29	I've tried to make sense of why this has happened.	-4	-3	-2	-4
30	It feels like a rollercoaster. I've felt terrified, so incredibly scared.	-2	0	-1	+3

Q sort statement		**F1**	**F2**	**F3**	**F4**
31	I avoid things about cancer, things on the TV, in the news, and places I see as being connected to the experience.	-3	-4	-3	+4
32	I feel as if I was chosen for this journey…it's a gift.	+1	-5	-6	-6
33	I have come to believe that if I can handle this, I can handle anything.	+5	0	-2	0
34	Alcohol and/or medication can help you manage how you feel.	+5	-6	-1	+5
35	Cancer has changed my view on the meaning of life.	+6	+1	-1	-4
36	Behind closed doors, I can get snappy and irritable.	0	-1	+4	-2
37	Sometimes I feel anxious, my heart beats fast, my head aches and that's when I'm thinking about the cancer.	-2	2	-2	5
38	I've developed valuable friendships with people in similar circumstances.	+2	+1	-2	-3
39	I feel like I'm on edge waiting for something awful to happen.	-6	0	+4	+2
40	The treatment is the barbaric bit, having it yourself or watching its effects.	0	-1	+4	+6
41	I've had upsetting nightmares which have left me feeling drained.	-3	-2	-4	-3
42	Parts of this experience have been horrendous and I feel like the memories of it are very powerful.	0	+2	+3	+2
43	I'm nervous to let out all the emotions I'm hiding, because if I opened up I'd fall apart.	-4	+3	+3	-5
44	Stories of how others have coped with cancer have changed how I view the illness.	+4	+1	-6	-4
45	People with cancer can feel disgusting, disfigured, or defected.	-1	-3	-3	+3
46	When I found out about the cancer the future ground to a halt. Things seem pointless now.	-6	0	-1	0
47	I've felt numb, almost as if I was dead inside.	-1	-2	-1	+3
48	Since finding out about the cancer, parts of my memory feel hazy, as if bits of it are missing.	+1	-2	+1	-3
49	The world has come to feel more dangerous and scary.	-1	-3	-4	-3
50	I look at how I've coped with all this and I think I'm a weak person.	-5	-5	-3	-1
51	Cancer teaches you that your own body can turn on you and let you down.	-1	+1	+2	+4
52	Cancer has made me rethink how I want to live my life. I've changed my priorities.	+3	+5	0	-2
53	I think the hardest part is always waiting to hear the results of tests.	0	0	+5	+2

Q sort statement		**F1**	**F2**	**F3**	**F4**
54	The worst bit was finding out that the cancer was incurable.	-4	+6	0	+4
55	I get tremendous pleasure from creating new memories. It motivates me and keeps me going.	+3	+3	-4	+1
56	Having earlier traumatic life experiences affects the way you cope with cancer.	+2	+2	+1	-4
57	Cancer causes you to appreciate the small things in life; you stop and smell the roses.	+5	+4	+2	+1
58	I feel like I've become more open to opportunities.	+1	-1	-4	-2
59	I have anger building up inside of me. I'm angry because I can't change anything.	-3	+1	-2	-2
60	I've felt like no one cares, like no one notices me.	-5	-5	0	-5
61	There have been times when I've felt spaced out and missed things people have said.	0	+2	-1	-3
62	There have been times when I've thought that cancer wasn't real, as if it wasn't happening.	+2	-4	0	+3