

# **Exploring the Traumatic Impact of Advanced Cancer**

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**Thesis submitted in partial fulfilment of the  
requirements of Staffordshire and Keele Universities  
for the jointly awarded degree of  
Doctorate in Clinical Psychology**

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### CANDIDATE DECLARATION

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<p>I confirm that the thesis submitted is the outcome of work that I have undertaken during my programme of study, and except where explicitly stated, it is all my own work.</p> <p>I confirm that the decision to submit this thesis is my own.</p> <p>I confirm that except where explicitly stated, the work has not been submitted for another academic award.</p> <p>I confirm that the work has been conducted ethically and that I have maintained the anonymity of research participants at all times within the thesis.</p> <p>Signed: _____ Date: _____</p>	

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### **Journal Submission Details**

The body of this thesis has been written for submission to the European Journal of Cancer Care. This journal aims to enhance comprehensive multi-professional cancer care, by providing essential reading on a range of topics, such as cancer prevention, treatment, and education. The editor welcomes contributions from research on supportive, palliative, and end of life care for individuals with cancer. Accordingly, the presented thesis aims to provide information to ensure better recognition and assessment of psychological distress and growth in those with Advanced Cancer (AC), and in the families of this population. As the European Journal of Cancer Care accepts both research reports and literature reviews, both paper one and paper two of this thesis will be submitted for consideration. These papers have been prepared in line with the formatting recommendations stated by the journal (Appendix A), with slight amendments being made to aid readability for thesis submission. Paper one and paper two have abided by the journal's word limit of 3000 to 8000 words (excluding tables, figures and references).

## **Thesis Abstract**

The number of individuals living longer after a diagnosis of advanced cancer (AC) is increasing. To provide effective care for this population, a sound understanding of the psychological impact of AC is necessary. Cancer has been shown to have a traumatic impact and can precipitate both post-traumatic stress (PTS) and post-traumatic growth (PTG). In individuals with cancer, PTS is manifested through intrusive thoughts and images related to the experience of cancer, avoidance of thoughts and feelings connected with this experience, hyper arousal, and negative changes to one's mood and thinking. PTG describes the positive changes that can occur in response to managing a challenging life event, such as cancer. While PTS and PTG have been explored extensively in response to primary cancer, the traumatic impact of AC has received less attention. A review of the literature on PTS in response to AC identified 11 studies, which were collated and critiqued. Across studies, individuals reported high rates of PTS, which were influenced by numerous factors. In completing this review, the researcher noted that studies on PTG in response to AC were lacking. There was also a paucity of qualitative research in this area, and few studies with the partners of those with AC, despite evidence of high rates of traumatisation in this group. To remedy these limitations in the evidence base, a Q-methodology study (n=11) was conducted. This study explored patients' and partners' responses to living with AC, to determine whether the constructs of PTS and PTG resonated with their subjective experiences. This analysis interpreted four differing accounts of the impact of AC, three of which could be understood as stories involving PTG and PTS. The final paper in this thesis provides a reflective account of the research experience.

# **Post-traumatic Stress in Response to Advanced Cancer: A Literature Review**

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## **Abstract**

Advances in medical treatment mean that the number of individuals living with a diagnosis of advanced cancer (AC) is increasing. To provide effective care for this population, health care professionals must have a sound understanding of the psychological impact of AC. Prior research has highlighted the prevalence of post-traumatic stress (PTS) in response to cancer. Current literature reviews on PTS and cancer are dominated by studies on individuals with primary cancer. Therefore, this literature review aimed to explore what is known about PTS in response to AC.

*Method:* Eleven studies of PTS and AC were identified via health electronic databases, of which, nine used the Impact of Events Scale (IES) to measure PTS, and eight were cross-sectional in nature.

*Results:* Across studies, high rates of PTS were reported in response to AC. Both cancer diagnosis and treatment were identified as being traumatic, and various factors were shown to influence PTS, such as age, physical well-being, prior trauma, depression, anxiety, and social difficulties. Given the dominance of quantitative studies in this area, research on the subjective experiences of those with AC is lacking and necessary, particularly in relation to the traumatic impact of this illness.

*Main Contribution:* This review has collated and critiqued studies on PTS and AC, in order to guide future research and provide preliminary recommendations for practice.

## **Keywords**

advanced cancer; psycho-oncology; post-traumatic stress disorder; literature review; adult; impact of events scale

## **Introduction**

### **The Scale of the Problem**

Each year, over 250,000 people in England receive a diagnosis of cancer, and while 1.8 million people are living with this diagnosis, 130,000 people die because of the disease (Department of Health, 2011). Cancer costs society approximately £18.3 billion per annum (Department of Health & Ellison, 2013), with NHS expenditure on cancer services in 2013 amounting to £5.8 billion (Nuffield Trust, 2014). Cancer has a financial, social, practical, and emotional impact on individuals (Brennan, 2004). Surveys indicate that “people fear cancer more than anything else” (Department of Health, 2011, p.7). In response to the overwhelming prevalence of cancer, the government has produced several key documents to influence the delivery of cancer care in the United Kingdom.

The National Institute for Clinical Excellence (2004) published guidance on *Improving Supportive and Palliative Care for Adults with Cancer*. This document promotes a holistic approach to the care of those with cancer, stating that “assessment...of patients’ needs for physical, psychological, social, spiritual, and financial support should be undertaken at key points” (National Institute for Clinical Excellence, 2004, p. 7). Given the connection between psychological and physical health (Ogden, 1996), and the prevalence of mental health difficulties in those with cancer (Fallowfield et al., 2001), a holistic approach, which includes psychological care is vital. Indeed, psychological intervention for those with cancer is equally as important as other forms of medical intervention (Department of Health, 2007). Yet the provision of psychological support is limited (National Institute of Clinical Excellence, 2004).

### **The Psychological Consequences of Cancer**

Scientific advances have resulted in better medical treatment for those with cancer, meaning that more individuals are living longer with cancer than ever before (Nezu & Nezu, 2007). While the prevalence of mental health problems in this patient group is high, these difficulties often go undetected

(Fallowfield et al., 2001) and only 61% of patients access mental health services (Singer et al., 2013).

The association between depression and cancer has received increased attention within the media (Mundasad, 2014) and academic literature; Hong & Tian (2014) found that 66.72% of people with cancer (n=1217) experienced depression. Reviews also highlight the prevalence of anxiety disorders within cancer populations (Stark & House, 2000). Adjustment disorder, a term describing either depressed or anxious mood or a combination of both, has been reported within 68% of patients with cancer (Derogatis et al., 1983). These figures emphasise the necessity of psychological support for those with cancer.

Policies frame cancer as a trauma (National Institute of Clinical Excellence, 2004) that has a “devastating human impact” (Department of Health, 2011), yet while they discuss anxiety and depression, they fail to mention post-traumatic stress (PTS<sup>1</sup>). However, research into PTS among individuals with cancer has increased considerably over the last two decades.

### **Post-traumatic Stress**

The Diagnostic and Statistical Manual of Mental Disorders (DSM-V) (American Psychiatric Association, 2013) states that individuals can experience PTS in response to an event involving actual or threatened death, injury, or sexual violence (criterion A). Individuals with PTS may re-experience (criterion B) this event through nightmares, intrusive memories, or dissociative reactions. They may try to avoid thoughts, feelings, or reminders of the event (Criterion C), and can feel hyper-aroused (Criterion E). Individuals with PTS can also experience negative changes in their mood and thinking: they may feel angry, fearful, numb, and can develop negative beliefs about themselves (e.g., I am worthless) and the world around them (e.g., the world is unfair) (Criterion D).

---

<sup>1</sup> Consistent with other researchers (Brennan, 2001, Joseph & Linley, 2005), the term post-traumatic stress (PTS) will be used throughout this paper to describe Post Traumatic Stress Disorder (PTSD) symptomatology experienced by individuals with cancer.

### **Explaining post-traumatic stress symptomatology.**

Theories on adapting to traumatic life events (Joseph & Linley, 2005, Horowitz, 1986) propose that an individual's ability to navigate through life is guided by a mental model of the world. This model develops in response to their life experiences, and encompasses beliefs and assumptions about themselves (e.g., I am in control), about the world (e.g., the world is safe and just), and about their goals (e.g., I will have children). Psychologically shocking events, such as a diagnosis of cancer, challenges this mental model, typically generating distress (Brennan, 2001). Individuals may then enter into a state of denial and avoidance in order to protect themselves from the severity of the trauma. However, their innate need to integrate the event into their pre-existing mental model means that information related to the trauma seeps into consciousness, causing re-experiencing of the event (Horowitz, 1986). Processing of trauma-related material occurs in a gradual manner as the individual oscillates between avoidance and re-experiencing, steadily revising their mental model to incorporate knowledge gained through the traumatic event. However, excessive use of defences (avoidance and numbness/denial) inhibits this processing, with trauma-related information remaining un-integrated, precipitating PTS (Brewin & Holmes, 2003).

### **Post-traumatic Stress and Cancer**

Traumatising events are those which are sudden and unexpected, and which generate a sense of intense loss of control and safety (Ehlers & Steil, 1995). Cancer can be conceived as a traumatic event, in that it threatens one's beliefs about control and safety, and exposes the frailty of the human condition (Brennan, 2001, Gurevich et al., 2002). Cancer differs to other traumatic stressors, being internally induced, being progressive, and occurring over a protracted period of time. These factors mean that cancer can be highly overwhelming and can generate intense distress (Gurevich et al., 2002). Individuals with cancer are exposed to a wide range of potentially traumatising experiences, such as receiving a life-threatening diagnosis, noxious treatments, distressing side effects, disfigurement, and disruption to one's physical, social, and occupational functioning (Kangas et al., 2002).

These experiences have led people to cite cancer as the “worst” trauma they have encountered (Alter et al., 1996).

There have been five literature reviews collating studies on PTS in those with cancer over the last fifteen years (Gurevich et al., 2002, Jim & Jacobson, 2008, Kangas et al., 2002, Neel, 2000, Smith et al., 1999a). The authors of each review highlighted the high rates of PTS experienced by this population. A considerable percentage of individuals with cancer have reported having intrusive thoughts and images related to their cancer diagnosis and treatment: 16% in Bleiker et al.(2000), 23% in Brewin et al. (1998), and 34% in Butler et al. (1999). High rates of avoidance of cancer-related stimuli have also been reported: 15% in Bleiker et al.(2000), and 28% in Butler et al. (1999). Smith and colleagues (1999a) have provided qualitative descriptions of PTS in those with cancer; one individual was “plagued by recurring distressing dreams concerning specific medical procedures” and experienced “extreme horror and nausea” (p.524) in revisiting the hospital site where she had received treatment. Another individual reported “intermittent flashbacks about the radiation” (p. 525) and avoidance of conversation and television programmes if related to medicine.

### **Diagnostic Issues.**

Despite the evidence of PTS among people diagnosed with cancer, recent amendments to the DSM (American Psychiatric Association, 2013) specify that a life threatening illness should not necessarily be considered as a traumatic event. Indeed, reports of the percentage of cancer patients meeting the full criteria for a robust diagnosis of PTSD are relatively low (Kangas, 2013), ranging from 0% (Mundy et al., 2000) to 32% (Naidich & Motta, 2000). These prevalence rates vary upon the assessment tool used (Kangas et al., 2002). The low percentage of diagnosable PTSD in those with cancer may also be due to the unique nature of cancer as a stressor. Firstly, individuals with cancer cannot adequately report symptoms of ‘avoidance’, as they cannot avoid an internally induced stressor (cancer) or life-saving treatment (Kangas et al., 2002). Secondly, the intrusive thoughts and images experienced by those with cancer are often future-focused, as



opposed to being related to past traumatic events (Gurevich et al., 2002). Finally, patients' reports of 'hypervigilance' may lack validity, as determining whether arousal is an organic symptom of cancer or a psychological symptom of PTSD is difficult (Gurevich et al., 2002, Kangas et al., 2002).

Despite difficulties in fulfilling PTSD criteria, as outlined by the DSM-V (American Psychiatric Association, 2013), high rates of PTS symptomatology persist among those with cancer and are concerning. Individuals who do not meet full DSM criteria, but are experiencing PTS symptomatology (partial PTSD) also experience clinically meaningful levels of social, interpersonal, and emotional impairment (Schnurr et al., 2000, Stein et al., 1997, Weiss et al., 1992). Therefore, research into PTS among those with cancer is of vital importance.

### **The Importance of Examining Post-traumatic stress in Advanced Cancer**

Current reviews on PTS in response to cancer are dominated by studies of patients with primary breast cancer (Gurevich et al., 2002, Jim & Jacobson, 2008, Kangas et al., 2002, Neel, 2000, Smith et al., 1999a). While PTS has been examined in those with Advanced Cancer (AC), these studies have not been appraised and summarised to guide practice. Examining the psychological consequences of AC (particularly its traumatic impact) is vital for many reasons. Firstly, the psychological needs of late-stage cancer patients are often overlooked, as their instrumental care needs are prioritised (Morasso et al., 1999), meaning the emotional components of the AC experience are disregarded (Greisinger et al., 1997). Secondly, there is a wealth of literature on anxiety and depression in AC, yet PTS in this population has received minimal attention, and available evidence is somewhat contradictory. While Akechi et al. (2004) found no incidences of PTS in individuals living with AC, the majority of researchers report high rates of PTS in response to AC. In a study by Meisel et al. (2012), 33% of women living with AC reported that their daily functioning was affected by PTS. Similarly, Butler et al. (1999) found that 52% of individuals with metastatic breast cancer reported high rates of PTS. Thirdly, PTS is more

common in individuals with AC, in comparison to those with early-stage cancer (Jacobsen et al., 1998), yet research efforts have been focused on the latter. Finally, in AC, PTS symptoms are correlated with higher suicidal ideation (Spencer et al., 2012), meaning that professionals must have a sound understanding of PTS in this population in order to ensure that their patients are as safe as possible.

### **Defining advanced cancer.**

Advanced Cancer (AC) is a term used to describe a cancer that is incurable, as it has metastasised by spreading from its original location to secondary sites (Low et al., 2007), or is based in one location but is considered inappropriate for curative treatment (American Cancer Society, 2014). While treatment is not used to cure AC, it is often used for symptom management and to ensure a better quality of life (American Cancer Society, 2014).

## **Method**

### **Aim of Paper**

The aim of this paper is to provide a current and comprehensive overview of the literature on AC and PTS, in order to provide guidance for future research and clinical practice. To achieve this aim, researchers have identified and appraised current evidence in this arena, paying particular attention to studies exploring variables (such as age) thought to be associated with PTS in this population. Whilst there have been five literature reviews on 'trauma and cancer' (Gurevich et al., 2002, Jim & Jacobson, 2008, Kangas et al., 2002, Neel, 2000, Smith et al., 1999a), these have been dominated by studies on those with breast cancer and early stage cancer. This review is therefore novel, being the first paper to home in on individuals with advanced disease, and to provide a critique of studies published in the last decade.

The literature review process involves systematic identification, amalgamation and critical evaluation of evidence (Aveyard, 2014). The researcher chose to examine and appraise studies published from 2004

onwards. This time frame was selected for various reasons. Firstly, one of the earliest key policies for AC care, *Improving Supportive and Palliative Care for Adults with Cancer* (National Institute of Clinical Excellence, 2004), was published in 2004. Secondly, examining studies from this date onwards permitted detailed reporting and critique of research published over the last decade, which was thought to be a satisfactory time period. Finally, current reviews focusing on PTS and cancer were published prior to 2004 (Gurevich et al., 2002, Kangas et al., 2002, Neel, 2000, Smith et al., 1999a), meaning that recent studies need to be examined. Whilst Jim and Jacobsen (2008) have published a more recent review, this was of poor quality, as it did not portray their search strategy, gave few details of studies included within the review and provided limited critique.

### **Searching the Evidence Base**

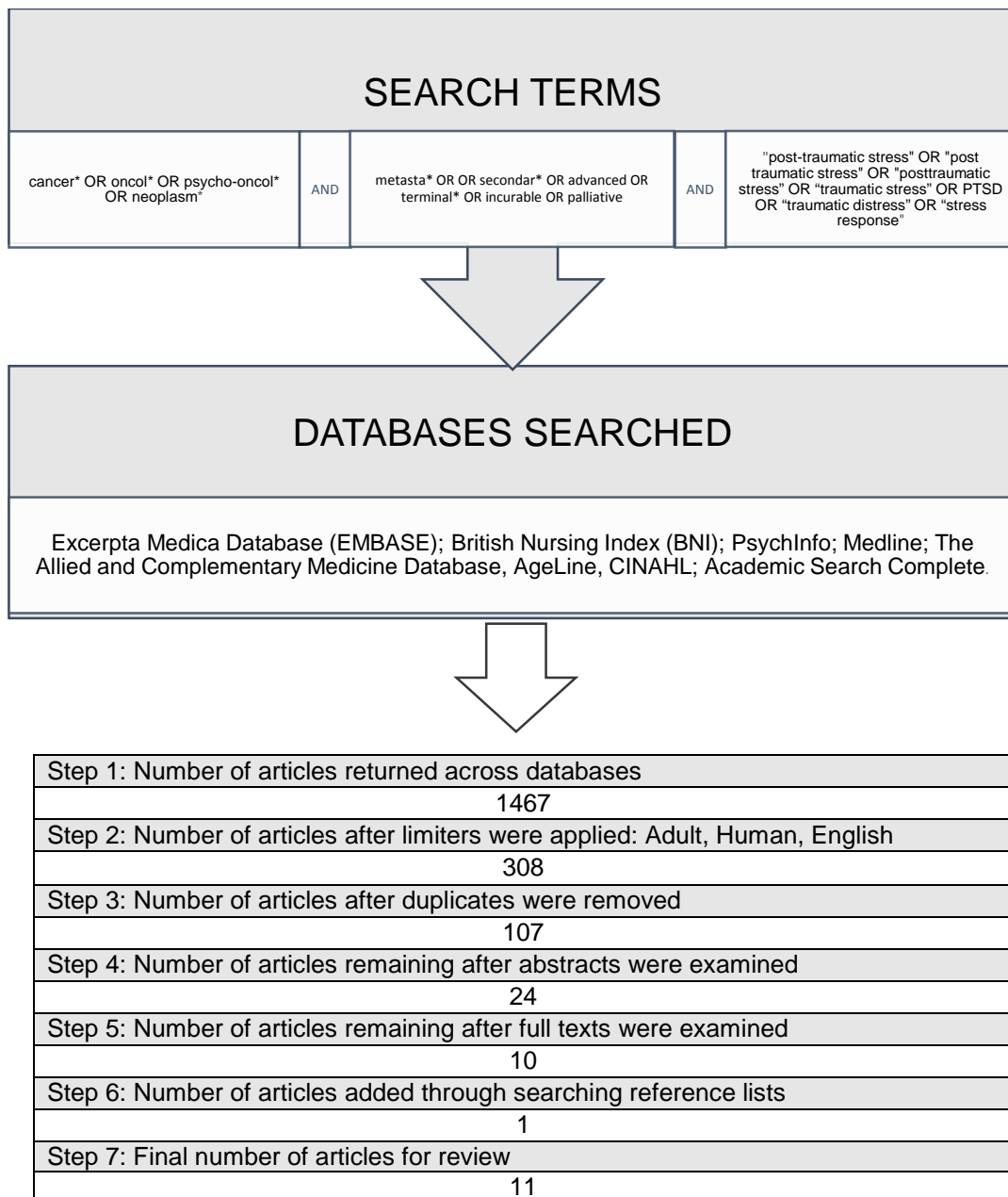
A scoping search (Booth et al., 2012) was completed, in which the evidence on PTS in AC was examined broadly, and key search terms were identified (Figure 1). The following databases were then used to ensure a comprehensive search of the literature: Excerpta Medica Database (EMBASE); British Nursing Index (BNI); PsychInfo; Medline; The Allied and Complementary Medicine Database; AgeLine; CINAHL; Academic Search Complete. The following criteria (Table 1) were applied to determine which papers should be included for review:

**Table 1: Inclusion and Exclusion Criteria**

Inclusion criteria	Exclusion Criteria
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papers in which participants were male or female (aged 18 years +)	papers that exclusively recruited people below the age of 18
papers that focused on PTS as a key topic, and that provided information on factors influencing PTS	papers examining adult parents' of those with paediatric cancer
papers in which the population of interest was those with AC, in which the cancer had metastasised or was locally advanced	papers focused on the prevalence of psychiatric disorders (or PTS) in AC
papers published from 2004 onwards	papers published before 2004
	papers which were not written in English.

The researcher and a peer researcher examined the titles and abstracts of the returned papers, assessing their adherence to the inclusion and exclusion criteria and their applicability to the research topic. The full texts of selected papers were accessed, and their reference lists were scanned to ensure that relevant papers not identified by the search strategy were included in the review (Figure 1).



**Figure 1: Literature Search Process**

### **Describing the Critical Appraisal Process**

The fundamental components of a critical appraisal of a research study involve evaluation of the appropriateness of the study design for the research question, and a careful assessment of the key methodological features of the design (Booth et al., 2012). Other factors that should be considered include the suitability of the statistical methods used, their

subsequent interpretation, and the relevance of the findings to one's own practice (Young & Solomon, 2009).

Patterns in the data and key findings across the selected studies were extracted and integrated to create an overarching synthesis of the studies (Booth et al., 2012). While there are no gold standard instruments for literature appraisal (Young & Solomon, 2009), the use of a specific appraisal tool ensures that all studies are analysed with equal rigour (Aveyard, 2014). As the papers under review adopted a range of designs, in order to ensure a fair critique, the researcher used a set of ten questions amalgamated from various critical appraisal tools (Crowe, 2013, Guyatt et al., 1995, Strengthening the Reporting of Observational Studies in Epidemiology [STROBE], 2007). These ten questions are presented in Appendix B.

## **Results**

An overview of the 11 studies that were reviewed and critiqued can be found in Appendix C. Within two of these studies (Mystakidou et al., 2011, Mystakidou et al., 2012a), clinical interview was used to measure PTS, while the *Impact of Events Scale* (IES) (Horowitz et al., 1979, Mystakidou et al., 2007a, Weiss & Marmar, 1997) was used in the remaining nine studies. Studies were categorized into groups based on their aims and designs. Three studies were focused on PTS in relation to specific aspects of the cancer experience, five studies were examining variables related to PTS, and the remaining three studies were on the relationship between PTS and preparatory grief. Each study was then critically appraised and rated in relation to various aspects of their design and reporting (Table 2). The reader is encouraged to consider these quality ratings in combination to reading the description of each study.

□

**Table 2: Critical Appraisal Ratings Summary**

Y- Fully met criteria PY- Partially met criteria N- Not met criteria N/A- not applicable	Mystakidou et al. (2007b)	Dooley et al. (2010)	Keuroghlian et al. (2010)	Yang et al. (2008)	Mystakidou et al. (2012a)	Posluszny et al. (2011)	Mystakidu et al. (2009)	Tsilika et al. (2009)	Mystakidou et al. (2011)	Kirchheiner et al. (2014)	Mystakidou et al. (2012b)

Did the study address a clearly focused question?	Y	Y	Y	Y	Y	Y	Y	Y	PY	Y	Y
Did the authors use an appropriate method to answer their question?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Were the subjects recruited in an acceptable way?	PY	PY	PY	Y	Y	Y	Y	Y	PY	Y	Y
Were variables accurately described/ measured to reduce bias?	Y	PY	PY	Y	Y	Y	Y	Y	Y	PY	Y
Is data collection replicable and was bias minimised?	PY	Y	PY	Y	Y	PY	N	PY	PY	PY	PY
Power calculation completed? And did sample size seem apt?	N	N	PY	N	PY	N	PY	PY	PY	N	PY
Were analyses complete and adequately described?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Is there a clear statement of findings?	Y	Y	Y	Y	Y	Y	Y	PY	PY	Y	Y
Can the results be applied to the local population?	PY	PY	N	PY	PY	PY	PY	PY	PY	PY	PY
Is the research valuable?	Y	PY	PY	Y	Y	Y	Y	PY	PY	Y	Y



## **The Cancer Experience**

Three studies honed in on specific stressors or time points within the AC trajectory (Mystakidou et al., 2012a, Kirchheiner et al., 2014, Posluszny et al., 2011).

Posluszny et al. (2011) used self-report questionnaires to examine PTS and perceived threat in response to the experience of: AC (n=22), early stage cancer (n=31), benign disease (n=33), no disease (n=22). Measures were taken prior to surgery, seven weeks post-surgery, and sixteen months after surgery. Participants with AC reported the highest level of threat at each assessment, which was positively associated with PTS. Thus, the more under threat participants felt, the more traumatic stress they experienced ( $P$ 's<0.001). Regardless of stage of illness, participants with cancer reported consistently higher levels of PTS ( $P$ <0.001), which declined over time after surgery ( $P$ =0.02). While Posluszny et al. (2011) used a longitudinal design, the high attrition rate (47%) may have given an inaccurate representation of PTS across groups, affecting the validity of comparisons.

Mystakidou et al. (2012a) interviewed 989 individuals living with AC, of which 17% were experiencing PTS. Of the participants with PTS, 67% percent identified their AC diagnosis as their traumatic stressor, responding to it with intense fear, helplessness, and horror. A further 10% of the participants with PTS identified the recent loss of a loved one as being the event that had triggered their PTS. Mystakidou et al. (2012a) found that participants' PTS symptom profiles were similar, regardless of the type of traumatic stressor they reported (cancer versus other event). Therefore, despite cancer being unique in comparison to more typical stressors, such as being assaulted (Gurevich et al., 2002, Kangas et al., 2002), it elicited a similar PTS response.

Mystakidou et al. (2012a) also found that participants with PTS were younger than those without PTS ( $P$ =0.01), and men were more likely than women to frame their cancer diagnosis as the most traumatic event they had experienced ( $P$ <0.005). Clinical characteristics (metastases, treatment,

opioids, cancer location) did not influence the development of PTS. However, other potential influencing factors were not assessed, such as the receipt of psychological therapy and time since diagnosis. Mystakidou et al. (2012a) used a structured clinical interview to assess participants PTS, which is a more reliable and valid method of assessment than self-report questionnaires, such as the IES (Gurevich et al., 2002).

Kirchheiner et al. (2014) used self-report questionnaires to examine Acute Stress Disorder (ASD) and PTS in response to brachytherapy treatment (n=50). Brachytherapy is a component of definitive radio(chemo)therapy, in which a high dose of radiotherapy is delivered directly to a cancerous tumour (Macmillan, 2013). Thirty percent of individuals presented with ASD one week post-treatment. These participants reported experiencing intrusive memories relating to their experience of treatment, hypervigilance and avoidance. At three months post-treatment, 41% of participants were experiencing PTS, with the majority of those who had ASD being in this group. Participants also reflected on their level of stress in response to treatment, rating Brachytherapy as most stressful, followed by chemotherapy, external beam radiation therapy, and finally laparoscopic lymph node staging. Regression analysis indicated that 82% of the variance in PTS scores could be accounted for by three pre-treatment variables: poor physical well-being ( $P=0.005$ ), higher levels of depression ( $P=0.024$ ), and lower emotional functioning ( $P=0.001$ ) were all found to enhance the likelihood of PTS. Prior trauma also appeared to enhance the likelihood of PTS, in that four participants reported a history of sexual violence and each went on to experience PTS in response to treatment. The longitudinal design of this study allowed Kirchheiner et al. (2014) to identify changes in PTS in response to a specific stressor (treatment), at specific times in relation to its occurrence. This is beneficial as it revealed how an individual's level of distress may fluctuate over the time period after treatment.

## **Summary.**

The findings from these studies indicate that living with AC can be traumatic, as shown by the high rates of reported PTS: 16% (Mystakidou et al., 2012a); 34% (Posluszny et al., 2011); 41% (Kirchheiner et al., 2014). However, they present contradictory evidence on the relationship between cancer treatment and PTS (Mystakidou et al., 2012a, Kirchheiner et al., 2014, Posluszny et al., 2011). This may be explained by the fact that different types of treatment are likely to elicit differing levels of distress. Similar to research on other cancers (Andrykowski et al., 2000, Green et al., 2000), both Mystakidou et al. (2012a) and Kirchheiner et al. (2014) found that prior trauma enhanced the likelihood of traumatization in response to cancer stressors. The inverse relationship between age and PTS in those with AC (Mystakidou et al., 2012a) has also been found in other studies on individuals with breast cancer (Cordova et al., 1995).

## **Factors Related to Post-traumatic Stress**

Five studies (Dooley et al., 2010, Mystakidou et al., 2007b, Mystakidou et al., 2009, Keuroghlian et al., 2010, Yang et al., 2008) were designed to examine the relationships between PTS and a range of variables.

Mystakidou et al. (2007b) used self-report questionnaires to explore the relationship between PTS and post-traumatic growth (PTG) in 58 individuals living with AC. PTG encompasses the positive changes that an individual can experience in response to managing highly challenging life events (Tedeschi & Calhoun, 2004). Within this study (Mystakidou et al., 2007b), participants were asked to rate their levels of PTS and PTG in response to their cancer diagnosis. Participants who experienced more PTS also reported more PTG ( $P=0.013$ ). These participants developed more meaningful and intimate interpersonal relationships ( $P=0.017$ ), a greater appreciation of life ( $P=0.001$ ) and an enhanced recognition of the new possibilities or paths for one's life ( $P=0.050$ ). Mystakidou et al. (2007b) also found positive relationships between specific PTS symptoms and aspects of PTG. Participants who developed a greater appreciation for life reported

more avoidance of cancer related stimuli ( $P=0.015$ ), more intrusions ( $P=0.005$ ), and felt more hyper-aroused ( $P=0.002$ ). Participants reporting more intrusions also experienced enhanced relationships ( $P=0.001$ ). However, multivariate analysis found overall PTS to be unrelated to PTG, indicative of the complex interplay between these two constructs referred to in other reviews (Jim & Jacobson, 2008).

Yang et al. (2008) assessed 65 participants with breast cancer recurrence. Questionnaires and clinical interviews were used to explore the relationship between traumatic stress, coping approaches, and mental health quality of life. 'Mental health quality of life' refers to mental health, role functioning, emotional functioning, social functioning, and vitality. Cancer diagnosis and treatment elicited PTS in 50% of participants. Disengagement coping, defined as denial or behavioural avoidance, mediated the impact of traumatic stress and physical symptom stress on quality of life ( $P=0.010$ ). Therefore, as participants' level of traumatic stress increased, they were more likely to utilise disengagement coping, which in turn worsened their mental health quality of life. The use of clinical interviews to gather data strengthens the validity of this study.

Mystakidou et al. (2009) used self-report questionnaire to explore the relationship between sleep quality, pain, psychological distress, and traumatic stress with 82 participants living with AC. Participants reported high rates of PTS in response to their cancer diagnosis. A total score of 33 on the IES-R indicates the presence of PTSD (Creamer et al., 2003). Within this study (Mystakidou et al., 2009), the mean score for Impact of Events Scale-Revised (IES-R) was 32.79. Data also revealed a weak but positive relationship between poor sleep quality and PTS ( $r=0.311$ ,  $P=0.004$ ), suggesting that individuals experiencing more traumatic distress had more disrupted sleep. Regression analysis indicated that 57.7% of the variance in sleep quality was predicted by PTS ( $P=0.01$ ), mental and physical quality of life ( $P's<0.0005$ ), although definitions for these quality of life indicators were not provided.

Dooley et al. (2010) also used questionnaires and clinical interviews to explore the psychological wellbeing of 49 men living with terminal cancer. All participants reported experiencing “significant levels” of PTS and significantly more symptoms of hyper-arousal, anxiety, anger, intrusion, avoidance, dissociation, and sexual difficulties than a normative group (all  $P$ 's<0.05). Reflecting on their experience of PTS, participants reported more symptoms of re-experiencing ( $M=2.51$ ) than either avoidance ( $M=2.14$ ) or hyper arousal ( $M=2.42$ ). Participants with severe PTS experienced more hyper-arousal, anxiety, social difficulties, depression, and psychological distress in comparison to participants with lower levels of PTS ( $P$ 's<0.05). Within this study, Dooley et al. (2010) have not explicitly stated whether participants were asked to complete the IES in relation to their experience of cancer. Therefore, while this study frames participants' PTS as relating to their illness, it may be related to an alternative stressor.

Keuroghlian et al. (2010) used interviews and self-report questionnaires to determine the relationship between hypnotisability, PTS, and depressive symptoms in 124 participants with metastatic breast cancer. Hypnotisability was positively and significantly related to overall PTS ( $P=0.03$ ), levels of intrusion ( $P=0.00$ ), and depression ( $P=0.03$ ). Further, PTS was positively and significantly related to hypnotisability, independent of symptoms of depression and hyper-arousal ( $P=0.03$ ). This relationship provides potential evidence for the proposal that high hypnotisability may enhance the likelihood of PTS (Keuroghlian et al., 2010).

### **Summary.**

These studies evidence the high rates of PTS in this group (Dooley et al., 2010, Mystakidou et al., 2009, Yang et al., 2008), highlighting the traumatic potential of AC. Whilst AC is distressing, the experience can also nurture positive changes, such as an enhanced appreciation for life (Mystakidou et al., 2007b). There were no common findings across studies to provide robust conclusions about the factors that influence PTS. However, the positive relationship between social difficulties and PTS in those with AC (Dooley et al., 2010) has also been found in earlier studies on women with

metastatic breast cancer (Butler et al., 1999) and other cancer types (Smith et al., 1999b).

### **Post-traumatic stress and Preparatory Grief**

The search strategy revealed three studies (Mystakidou et al., 2011, Mystakidou et al., 2012b, Tsilika et al., 2009) on the relationship between PTS and preparatory grief. 'Preparatory Grief', refers to the grieving process occurring as people prepare for their separation from the world and loss of self (Kübler-Ross, 2003). This grieving can entail episodes of crying, sadness, and anxiety, whilst the individual undergoes emotional, social, spiritual, physical, cognitive, and behavioural modifications in identifying and adjusting to their losses (Peryakoil & Hallenbeck, 2002).

Tsilika et al. (2009) used self-report questionnaires to explore the relationship between PTS and preparatory grief with 94 individuals living with AC. Participants were asked to rate their levels of PTS in response to their cancer diagnosis. A positive and significant relationship was found between preparatory grief and all indicators of PTS: avoidance ( $P<0.0005$ ), intrusion ( $P<0.0005$ ), and hyperarousal ( $P=0.0005$ ). Similarly, there was a significant positive relationship between preparatory grief, and overall PTS ( $P<0.0005$ ). Thus, participants who were more distressed by their impending death were also likely to be experiencing greater preparatory grief. Multiple regression analysis revealed that 51.1% of the variance in preparatory grief scores could be predicted by four variables: individuals who were younger in age ( $P=0.011$ ), who had poorer physical wellbeing ( $P=0.061$ ), and had higher rates of intrusion ( $P=0.019$ ) and hyper-arousal ( $P<0.0005$ ) experienced more preparatory grief. In sum, a person's experience of preparatory grief is related to their age, and the traumatic and physical impact of their advancing disease (Tsilika et al., 2009).

Using the same sample, Mystakidou et al. (2011) sought to further explore the influence of anxiety upon the relationship between PTS and preparatory grief. Statistically significant positive associations were found between all PTS scales and anxiety: avoidance ( $P<0.0005$ ), intrusion ( $P<0.0005$ ), and hyperarousal ( $P<0.0005$ ), suggesting that levels of

traumatic stress increase in parallel to a person's anxiety. Anxiety was also positively associated with preparatory grief ( $p < 0.0005$ ). In examining the role of anxiety in the relationship between PTS and preparatory grief, Sobel test calculations, a method to test the significance of a mediation effect, were significant ( $P's < 0.0005$ ). This indicated that anxiety partially mediated the relationship between each PTS scale and preparatory grief; PTS led to anxiety, which in turn influenced preparatory grieving.

Mystakidou et al. (2012b) went on to explore the relationship between PTS, preparatory grief and sociodemographic variables in those with AC. Individuals with PTS were statistically more likely to be younger than those without PTS ( $P = 0.01$ ) and were more likely to be experiencing preparatory grief ( $P = 0.003$ ). Mystakidou and colleagues (2012b) also found a significant difference in rates of PTS in patients with metastatic disease compared with those whose cancer was locally advanced ( $P = 0.05$ ).

### **Summary.**

These studies indicate that participants who perceived their AC as more traumatic were also experiencing more preparatory grief (Mystakidou et al., 2011, Mystakidou et al., 2012b, Tsilika et al., 2009). As preparatory grief is arguably inevitable in facing one's own death, PTS may be fundamental in the process of adjusting to AC, as suggested by theoretical models of adapting to life threatening events (Brennan, 2001, Joseph & Linley, 2005). Mystakidou et al. (2011) suggest that the relationship between grief and stress may explain why some individuals can navigate through the process of preparatory grief more easily than others. Preparatory grief may intensify as death becomes imminent, and may become problematic for those with traumatic stress, who are unable to express the distress that occurs within the grief response (Mystakidou et al., 2011).

### **Qualitative Reports of Post-traumatic stress in Advanced Cancer**

The search revealed three publications containing descriptions of PTS in those with AC, one of these being a case report (Udo & Gash, 2012). The other two papers were quantitative studies which included qualitative data to

supplement their findings (Dooley et al., 2010, Kirchheiner et al., 2014). While the case report did not qualify for rigorous critical appraisal (Critical Appraisal Skills Programme, 2013), it is still worthy of reporting, as it contributes to what is known about PTS in response to AC.

Udo and Gash (2012) published a case report on a woman with terminal lung cancer who withdrew from cancer treatment as a result of complex PTS. Eye Movement Desensitization and Reprocessing (EMDR), breathing exercises, and clinical hypnosis were combined with pharmacotherapy (mirtazapine and quetiapine) to treat the patient's distress. A visual description of how PTS may present in AC was provided. For example, avoidance was seen in the patient's refusal to discuss "death and all that" (p.2), and her declining of group work. The report also highlighted how medical investigations acted as a trigger for traumatic emotions. Udo and Gash (2012) provide a clear description of the psychological interventions used. However, they measured the effectiveness of the intervention with the Hospital Anxiety and Depression (HADS) scale (Zigmond & Snaith, 1983), despite the client not being described as depressed. They also failed to report the outcome scores from this scale.

While Kirchheiner et al. (2014) focused mainly on their aforementioned quantitative findings, they also gathered qualitative information on participant's "helpful and stressful" (p. 265) experiences during brachytherapy treatment. The support of the treatment team, psychological support, and maintaining a positive attitude were reportedly helpful. In contrast, pain, organizational problems, and immobility during the treatment procedure enhanced stress. Kirchheiner et al. (2014) also presented participants' reflections about treatment, such as "I will never forget the mental images of myself lying there like a half woman" (p. 265), and "I don't want to feel my vagina anymore, otherwise the memories come up" (p. 265). These verbatim quotes demonstrate the types of cancer related intrusions that can occur post-treatment. Similarly, Dooley et al. (2010) gathered qualitative data, which highlighted the fundamental contribution of physical symptoms to a person's distress. Participants described how



physical symptoms reminded them of their illness, triggering intrusive thoughts, anger, and anxiety, which impacted on their interpersonal relationships.

### **Summary.**

Overall, these researchers (Dooley et al., 2010, Kirchheiner et al., 2014, Udo & Gash, 2012) would have benefitted from making participants' qualitative data a more substantive part of their studies. However, Dooley et al. (2010) and Kirchheiner et al. (2014) have used qualitative data to highlight key factors which impact on a patient's experience and wellbeing. Udo and Gash (2012) are the first practitioners to report on the treatment of PTS in AC; they emphasise that studies on psychological intervention are vital as, in the absence of a sound evidence base, professionals may be more prone to using sedating medication to reduce anxiety. The use of such medication could diminish an individual's quality of life, and their ability to interact with other individuals in the final months of their life.

## **Discussion and Critique of the Evidence Base**

### **Reporting of Studies**

Across the evidence base, studies addressed a clearly focused question and gave ample rationale for their study. Each study recruited participants in an ethical manner, operationalised their variables of interest, and provided clear details of their methodological procedures and statistical analyses. This level of detail will permit replication of studies to enhance the reliability of findings over the coming years.

### **Sampling**

None of the studies used a power calculation in deriving their sample size, and so it is not clear whether they recruited enough participants to avoid a type II error and to detect an effect where one existed. Further, the external validity of findings in this evidence base are limited, as a large percentage of the studies were conducted by the same research team (Mystakidou et al., 2007b, Mystakidou et al., 2009, Mystakidou et al., 2011,

Mystakidou et al., 2012a, Mystakidou et al., 2012b, Tsilika et al., 2009). These studies recruited participants from the same palliative care unit, and do not state the ethnicity of participants. This limits the generalisability of the findings, as these participants may represent poorly individuals from other countries receiving care within a different cultural, financial, and health care context. However, all the studies reported a range of other demographic factors such as age, gender and years in education which permits clinicians to determine the similarities between participants and their local population based on these factors.

The external validity of reported data is also limited by the fact that many patients with PTS may not willingly participate in research, given that a key symptom of PTSD is “avoidance” (American Psychiatric Association, 2013). Therefore the incidence of PTS reported within empirical studies is likely to be an underestimation and those participating are likely to be less distressed than patients within clinical settings.

## **Design and Measurement**

While, two studies used a structured clinical interview to assess PTS (Mystakidou et al., 2012a, Mystakidou et al., 2012b), the remaining eight used self-report questionnaires. Self-report questionnaires can have numerous drawbacks. Firstly, questionnaires predefine what information is to be collected from participants (Haralambos et al., 2002). For example, participants may have wished to provide information on the experience of cancer-related intrusions, but a predefined scale may not provide the opportunity to share such reflection. Secondly, three studies (Dooley et al., 2010, Kirchheiner et al., 2014, Mystakidou et al., 2009) used numerous lengthy questionnaires, which could have resulted in habituation or acquiescence, impacting on the accuracy of the participants' responses. Eight studies (Dooley et al., 2010, Kirchheiner et al., 2014, Mystakidou et al., 2007b, Mystakidou et al., 2009, Mystakidou et al., 2011, Posluszny et al., 2011, Tsilika et al., 2009) required participant's to complete questionnaires in the absence of the researcher. This meant, for example, that participants were not able enquire about ambiguous items, which may have resulted in

misinterpretation. However, all the studies measuring PTS via a self-report questionnaire used various versions of the Impact of Events Scale (IES) (Horowitz et al., 1979, Mystakidou et al., 2007a, Weiss & Marmar, 1997), each of which have sound psychometric properties (Creamer et al., 2003, Horowitz et al., 1979, Mystakidou et al., 2007a, Sundin & Horowitz, 2002, Weiss & Marmar, 1997)

The majority of studies were cross-sectional in nature, in that they measured PTS and a range of other variables at one time point. This is problematic, as PTS is not a stable construct and is known to fluctuate over time in those with cancer (Kangas et al., 2002). Nevertheless, cross-sectional studies can gain a wealth of data on important variables and take little time (Levin, 2006), making it an apt design in an area where there is minimal research, and in which participants are likely to be easily fatigued or in pain.

### **The Dominance of Quantitative Research**

While Dooley et al. (2010) and Kirchheiner et al. (2014) collected supplementary qualitative data, the evidence base is generally limited by its reliance on quantitative studies. This means that the in-depth experience of the traumatic impact of AC on an individual's day-to-day life remains under-researched. Quantitative studies use measures, such as the IES, which generate aggregate outcome scores reflecting the frequency of PTS symptoms. Thus, this data provides no insight into the individual's holistic experience, or the qualitative features specific to PTS in those with AC.

### **Synthesising the Findings**

The evidence base for PTS in response to AC is very limited, and many findings need validating through further studies. Nevertheless, in order to summarise current evidence, findings have been collated to generate preliminary recommendations for assessing and managing PTS in this population.

## **Preliminary Recommendations for the Assessment and Management of PTS in AC**

- Researchers have identified a high incidence PTS in those with AC (Dooley et al., 2010, Kirchheiner et al., 2014, Mystakidou et al., 2009, Mystakidou et al., 2012a, Posluszny et al., 2011, Yang et al., 2008). Therefore, health care professionals should maintain an awareness of the potential of AC to traumatise individuals, and should be able to recognise and assess traumatic distress in this population.
- Across the cancer trajectory, diagnosis has been highlighted as a key stressor eliciting PTS (Mystakidou et al., 2009, Mystakidou et al., 2012a, Yang et al., 2008). Subsequent to being diagnosed, patients have to accommodate important information regarding their health and often need to make decisions in relation to treatment. Health care professionals should include assessment of PTS within their standard assessment protocol during this time. They should also consider whether individuals need specialist psychological support.
- As the presence of Acute Stress Disorder (ASD) enhances the likelihood of PTS at a later stage (Kirchheiner et al., 2014), health care professionals should remain alert for signs of ASD to offer early intervention and prevention of PTS.
- In assessing a patient's physical and psychological well-being, health care professionals should remain aware of factors that have been shown to be related to PTS, such as, being younger in age, being male (Mystakidou et al., 2012a), having experienced prior trauma (Kirchheiner et al., 2014, Mystakidou et al., 2012a), poorer physical functioning (Kirchheiner et al., 2014), low mood (Dooley et al., 2010, Kirchheiner et al., 2014), anxiety (Dooley et al., 2010, Mystakidou et al., 2011), somatic complaints, social difficulties (Dooley et al., 2010), preparatory grief (Mystakidou et al., 2011, Mystakidou et al., 2012b, Tsilika et al., 2009) and metastatic disease (Tsilika et al., 2009).
- As research has demonstrated that individuals can experience positive changes as a result of living with AC (Mystakidou et al., 2007b), health care professionals should remain alert for signs of

personal growth, such as developing more meaningful relationships or an increased appreciation of life. Helping individuals to identify positive consequences in response to a traumatic event, such as AC, may further enhance their wellbeing (Joseph & Linley, 2005).

- During treatment, patients should be provided with a supportive treatment team, the option of psychological intervention, and sound pain management, as these factors are beneficial in ensuring that a patient feels supported (Kirchheiner et al., 2014).
- As poor sleep and PTS are associated (Mystakidou et al., 2009), when managing a patient's sleep disruption, health care professionals should consider the presence of traumatic stress (in addition to the multitude of other factors that can impact on sleep), and should avoid immediately resorting to pharmacological treatment.
- Individuals with AC have reported that pain can trigger intrusions about death and illness, which then impact on an individual's psychological well-being and interpersonal life (Dooley et al., 2010). Psychological treatment should therefore provide patients with guidance on how to manage intrusions triggered by the physical symptoms of cancer.
- In individuals with PTS, implementing psychological intervention that discourages the use of disengagement coping is vital to ensure a better quality of life (Yang et al., 2008).
- High rates of anxiety and PTS may prevent individuals from expressing their distress in relation to their impending death, disrupting the process of preparatory grieving (Mystakidou et al., 2011). In these circumstances, patients should be offered interventions for both PTS and anxiety, with the aim of facilitating preparatory grieving.

### **Implications for Researchers**

Recommendations for future research echo those suggested by previous reviewers (Jim & Jacobson, 2008, Kangas et al., 2002); more systematic study on the traumatic impact of cancer is necessary. It is

particularly important to explore PTS in AC, as studies in this area are relatively sparse, and there is some contradiction about the prevalence of PTS. While studies presented in this review suggest that AC is common in this population, as mentioned, a study exploring the prevalence of mental health difficulties in those with terminal cancer found no incidences of PTS (Akechi et al., 2004). Quantitative studies should utilise larger and more representative samples, and should focus on specific aspects of the AC experience, such as disfigurement or hospital admission, to identify specific traumatic stressors. Further, longitudinal studies that map an individual's levels of PTS from AC diagnosis to death would also be valuable, as they might indicate stages at which individuals are likely to need specialised psychological support.

Research on 'AC and trauma' has also identified high rates of PTS in the partners of those with AC (Butler et al., 2005, Posluszny et al., 2014), yet this group are generally understudied. Further, while growth has been studied in response to other cancers (Fromm et al., 1996, Sears et al., 2003), PTG in response to AC has received less attention. Therefore, future research should seek to include the partners of those with AC, and should also explore the potential for individuals to grow and be resilient in facing this disease.

Qualitative research is also necessary to understand the traumatic nature of AC as lived by patients. There exists a lack of understanding about the distinct features of PTS in those with cancer (Kangas et al., 2002). In addition, while the majority of quantitative studies suggest that traumatic distress is common in responding to AC, this has not yet been supported by qualitative data. In summary, studies which explore the subjective experiences of this population are necessary to gain insight into people's individualised response to AC, and to determine the qualitative nature and prevalence of traumatic distress within this group.

## **Conclusion**

The high rates of PTS reported across studies in this review highlights the traumatic potential of AC, and emphasises the importance of research in

this area. The absence of common findings across studies means that robust conclusions on factors affecting the development of PTS in this population cannot be made. However, as with research on individuals with other cancers, studies presented in this review suggest that being younger in age, having poorer social support, and having experienced prior trauma may enhance the likelihood of PTS in response to AC. As current research in this area is predominantly quantitative in nature, future studies should examine the subjective experiences of people living with AC, to better determine both its traumatic impact and the nature of PTS within this population.

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## Appendices

### Appendix A: Journal Submission Details

Impact Factor: 1.762

ISI Journal Citation Reports © Ranking: 2013: 14/69 (Rehabilitation (Social Science)); 15/105 (Nursing (Social Science)); 16/107 (Nursing (Science)); 20/63 (Rehabilitation); 40/86 (Health Care Sciences & Services); 150/203 (Oncology)

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### Author Guidelines

#### Manuscript Types

The *European Journal of Cancer Care* publishes original research reports, literature reviews, guest editorials, letters to the Editor and special features on current issues affecting the care of cancer patients.

The Journal does not publish case reports, case studies, or short communications, and these will be rejected without review if submitted.

#### Manuscript Style

Manuscripts should usually be between 3,000 and 8,000 words in length, excluding references, figures, and tables. The manuscripts **must** contain:

##### *Title page*

This should contain a concise, descriptive title of the article, the names and qualifications of all authors, their job titles, affiliations and full mailing address, including email addresses and fax/telephone numbers. The title page must also contain details of any source(s) of support in the form of grants, bursaries, free use of equipment, drugs or any other benefits which should be disclosed. The e-mail address of a corresponding author must be provided for correspondence purposes and the Editorial Office alerted of any changes to this if necessary.

##### *Abstract*

This should be written as a single paragraph of no more than 200 words. It should not contain subheadings and should be on a separate page. Where appropriate, authors should ensure that the abstract describes the purpose, population, methodology, sample, setting and details of the variables under study. It should also highlight the outcome measures and main conclusions of the study. The abstract should accurately reflect the title and should be followed by no more than six keywords (see below).

##### *Main Text*

This should begin on a separate page, and include an introduction, methods, results, and a discussion section. Reviews must contain a clear exposition of the

search strategy, databases, keywords and any selection/evaluation criteria used in the review where appropriate. Authors should avoid using abbreviations, acronyms and footnotes. The use of non-discriminatory language is encouraged and spelling should conform with that used in the Concise Oxford Dictionary of Current English by setting any spell checker used to UK English (not US English). Manuscripts must clearly specify that ethical approval has been obtained for the study where required.

### *References*

Should be in the Harvard style. Authors' names should be cited in the text followed by the date of publication, e.g. Smith and Parker (2008) or (Smith and Parker, 2008) as appropriate. Where three or more authors are cited, the first author's name followed by et al. should be written in the text, e.g. Williams et al. (2009) or (Williams et al, 2009) where required.

The reference list should start on a separate page. References should be listed in alphabetical order as per the following examples. Page numbers from books need only be included when quoting or paraphrasing directly. Unpublished work should only be cited in the text (with all authors' surnames and initials). Only references to articles genuinely in press should be included in the reference list.

### *Tables*

Should include only essential data. Each table must be typewritten on a separate sheet and should include a clear title. Tables should be numbered in the same way as figures and listed on a separate page at the back of the manuscript.

### *Titles, Keywords and Discoverability*

The Journal places great weight upon the electronic discoverability of its papers. Manuscript titles and keywords should therefore, accurately portray the scope of the paper and include words pertaining to the population or sample, the method of inquiry, any tools or measures used and its key findings as appropriate. These words should be reiterated at least once in the abstract. Titles should be clear, descriptive, and avoid the use of metaphor, elaborate language or respondent quotations which are less likely to be discovered by the electronic algorithms of modern search engines.



## Appendix B: Critical Appraisal Tool

QUESTION	Study 1	Study 2	Study 3	Study 4	Study 5	Study 6	Study 7	Study 8	Study 9	Study 10	Study 11
1. Did the study address a clearly focused question? Consider: hypotheses and rationale											
2. Did the authors use an appropriate method to answer their question?											
3. Were the subjects recruited in an acceptable way? Consider: ethics, selection bias											
4. Were variables accurately described and measured to reduce bias?											
5. Is data collection replicable and was bias minimised? Consider: instructions, self-report											
6. Was a power calculation completed? And did sample size seem apt?											
7. Were analyses and findings adequately completed and described?											
8. Is there a clear statement of findings? Consider: original hypotheses.											
9. Can the results be applied to the local population? Consider: external validity											
10. Is the research valuable? Consider: Int. validity, Trust agenda, review question											

## Appendix C: Summary of Studies

Author/Y ear	Origin	Aim	Participants	Variables and their Measures	Findings
Posluszny et al. (2011)	USA	To examine levels of perceived threat and PTS at different time points in relation to surgery.	AC (n=22); early stage cancer (n=31); benign disease (n=33); no disease (n=22).	- <b>Perceive Threat</b> (3 item measure) - <b>PTS</b> (IES) (PCL-CL)	-Threat significantly correlated with IES scores at each assessment ( $r$ 's = 0.46, 0.48, and 0.50; all $P$ 's<0.001). There was also a significant group by time interaction effect on threat scores ( $F$ [4,138.5] = 6.96; $P$ <0.001). Tukey HSD procedures demonstrated that those with AC experienced the most threat. - IES scores were markedly higher for disease groups in comparison to no disease groups ( $F$ [3,104.2] = 11.19; $P$ <0.001) but were not significantly different from one another. - IES scores declined over time, most markedly for three disease groups ( $F$ [6,163.8] = 2.60; $P$ = 0.02).
Mystakidou et al (2012a)	Greece	To examine traumatic stressors and differences between participants with/without PTS.	n=989 (M=64.41 years)	- <b>Trauma History</b> (SCID- 1 from DSM-IV-TR: The traumatic event screening query from the PTS module) - <b>Defining traumatic event</b> (interview)	-170/989 participants presented with PTS, of which 66.7% pinpointed their cancer diagnosis as their traumatic event. - Participants with PTS were younger ( $63.54 \pm 12.07$ ) than those without PTS ( $70.36 \pm 13.03$ ; $P=0.01$ ). -Men (54.6%) were more likely than women (35%) ( $P<0.005$ ) to frame their cancer diagnosis as their most traumatic event.
Kirchheiner et al. (2014)	Austria	To investigate ASD and PTS in response to cancer.	n=50 patients (M=54 years)	- <b>ASD/PTS</b> (IES-R) - <b>Anxiety and depression</b> (HADS) - <b>Physical functioning</b> (ECOG) - <b>Stress rating</b> (a scale of 0-10, with 10 indicating maximum stress). - <b>Quality of Life (incl. of emotional functioning)</b> (EORTC-QLQ-C30) - <b>Helpful and unhelpful</b>	-ASD occurred in 30% of participants 1 week post-treatment. -PTS occurred in 41% of participants 3 months post-treatment. - Brachytherapy was rated as more stressful (median 8), than chemotherapy (median 5), external beam radiation therapy (median 3) and laparoscopic lymph node staging (median 2).

				<b>experiences:</b> (interview)	-In a model explaining 82% of variance in IES scores, poor physical performance status (P=0.005), higher levels of depression (P=0.024), and lower emotional functioning (P=0.001) were found to be significant pre-treatment predictive variables.
Mystakidou et al. (2007b)	Greece	To investigate the relationship between PTS and PTG.	n=58	<ul style="list-style-type: none"> <li>- <b>PTS</b> (IES-R-GR and its subscales: 'Avoidance', 'Intrusion' and 'Hyper arousal')</li> <li>- <b>PTGI</b> (PTGI and its subscales: 'Relating to Others', 'New Possibilities', 'Personal Strength', 'Spiritual Change', and 'Appreciation of Life')</li> </ul>	<ul style="list-style-type: none"> <li>- Significant associations between IES score and the following variables: 'Relating to Others' (r= 0.311, P=0.017), 'New Possibilities' (r = 0.248, P=0.050), 'Appreciation of Life' (r= 0.419, P=0.001) and overall PTGI scores (r=0.323, P=0.013).</li> <li>- 'Appreciation of Life' was significantly associated with: 'Avoidance' (r= 0.318, P=0.015), 'Intrusions' (r=0.365, P=0.005) and 'Hyper arousal' (r=0.398, P=0.002).</li> <li>- 'Relating to Others' and 'Intrusion' (r=0.414, P=0.001) also showed significant correlation.</li> <li>-All significant relationships demonstrated a positive association and had weak-moderate effect sizes.</li> </ul>
Yang et al. (2008)	USA	To examine disengagement versus engagement coping in the relationship between traumatic stress and mental health quality of life.	n=65 (M=54 years, SD=11)	<ul style="list-style-type: none"> <li>-<b>PTS</b> (IES)</li> <li>- <b>Coping strategies</b> (Brief COPE)</li> <li>-<b>Quality of Life- Mental health</b> (Mental Health Component Summary from the SF-36)</li> </ul>	<ul style="list-style-type: none"> <li>-The model testing disengagement coping as a mediator between PTS and MCS [<math>\chi^2(2) = 1.221</math>, <math>p=0.543</math>; RMSEA=0.000; CFI=1.000] revealed a good fit to the data and explained 36% of the variance in MCS at follow-up.</li> <li>-Paths from PTS to disengagement coping, and from disengagement coping to MCS were significant (<math>P&lt;0.05</math>), whereas the path from PTS to MCS was non-significant (<math>p=0.916</math>).</li> <li>-The mediation effect from PTS to MCS through disengagement coping was significant (bias-corrected 95% CI: -0.275, -0.035, <math>P=0.010</math>).</li> </ul>

Dooley et al. (2010)	Australia	To examine the psychological impact of terminal lung cancer (Mesothelioma).	n=49 (M=51.1 years)	<p><b>- Traumatic stress</b> (IES and TSI measuring anxiety/arousal, depression, anger, intrusions, avoidance, dissociation, sexual difficulties, impaired self-reference, and tension reduction behaviour)</p> <p><b>-Depression</b> (CES-D)</p> <p><b>-General psychological health</b> (GHQ measuring anxiety, somatic complaint, social dysfunction, depression and overall distress; SCL-90 measuring somatization, obsessive-compulsiveness, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoid ideation, psychoticism, symptom severity and intensity)</p>	<p>- TSI scores higher than the normative group for 6/10 scales (all <math>P</math>'s&lt;0.05, <math>r</math>'s= 0.35-0.78).</p> <p>-Significant associations were found between 59/60 TSI subscales, GHQ subscales, and CES-D (all <math>P</math>'s&lt;0.05. <math>P</math>&lt;0.01, or <math>P</math>&lt;0.001, <math>r</math>'s=0.24-0.68).</p> <p>-Man Whitney U revealed significant group differences for Severe versus Mild stress on: all IES symptoms subscale (<math>P</math>'s=0.02-0.04, <math>r</math>'s=0.46-0.64), all GHQ subscales (<math>P</math>&lt;0.001-<math>P</math>=0.003, <math>r</math>=0.48-0.66), SCL-90-R symptom severity (<math>P</math>=0.001, <math>r</math>=0.87) and symptom intensity (<math>P</math>&lt;0.001, <math>r</math>=0.81).</p> <p>-Man Whitney U revealed significant group differences for Severe versus Moderate stress on: anxiety (<math>P</math>=0.04, <math>r</math>=0.37), hyper-arousal (<math>P</math>=0.018, <math>r</math>=0.41), social dysfunction (<math>P</math>=0.04, <math>r</math>=0.35), severe depression (<math>P</math>=0.02, <math>r</math>=0.41), Overall GHQ (<math>P</math>=0.01, <math>r</math>=0.43), symptom intensity (<math>P</math>&lt;0.001, <math>r</math>=0.70).</p>
Mystakidou, et al. (2009)	Greece	To assess the relationship between sleep quality, pain, psychological distress, cognitive status and post-traumatic experience.	n=82 (M=62.65 years)	<p><b>-Sleep Quality</b> (PSIQ)</p> <p><b>-PTSD</b> (IES-R)</p> <p><b>- Mental (MCS) and Physical Quality of Life (PCS)</b> (SF-12)</p>	<p>-Significant associations were found between PSQI and IES-R (<math>r</math>=0.311, <math>P</math>= 0.004).</p> <p>-Using a stepwise method, a significant MR model emerged (<math>F</math>[3, 78]=35.49, <math>P</math>&lt;0.0005), in which MCS (<math>B</math>=-0.146, <math>P</math>&lt;0.0005), PCS (<math>B</math>=-0.184, <math>p</math>&lt;0.0005) and IES-R (<math>B</math>=0.070, <math>P</math>= 0.010) accounted for 57.7% of the variance in PSIQ score.</p>
Keuroghlian et al. (2010)	USA	To determine whether high hypnotisability is associated with PTS and depressive symptoms.	n=124 (M=53.1 years, SD=10.6).	<p><b>-Hypnotisability</b> (HIP, scores were dichotomized into high and low categories)</p> <p><b>-Depression</b> (CES-D)</p> <p><b>-PTS</b> (IES)</p> <p><b>-Hyper-arousal</b> (POMS)</p>	<p>-HIP was significantly associated with IES total (<math>r_s</math>=0.19, CI= 0.09-0.42, <math>P</math>= 0.0312), and IES intrusion (<math>r_s</math> = 0.26, CI=0.09-0.42, <math>P</math> = 0.0034) .</p> <p>-IES total score remained significantly associated with hypnotizability after adjusting for depressive symptoms and hyper-arousal.</p>

Tsilika et al. (2009)	Greece	To examine the relationship between PTS and preparatory grief.	n= 94 (M=63.7 years)	<b>- PTS</b> (IES-R-Gr and subscales: avoidance intrusion, hyper-arousal) <b>-Preparatory Grief</b> (PGAC) <b>-General wellbeing:</b> Performance Status (ECOG/WHO)	-Significant correlations were found between PGAC and all scales on the IES-R-Gr: avoidance ( $r= 0.537$ , $P<0.0005$ ), intrusion ( $r=0.607$ , $P<0.0005$ ), hyper-arousal ( $r=0.645$ , $p=0.0005$ ) and total IES-R ( $r=0.70$ , $p<0.0005$ ). - Using a forward method, a significant MR model emerged ( $F[4, 89] = 22.01$ , $P<0.0005$ ) in which age ( $B=-0.18$ , $P=0.011$ ), poor performance status ( $B=4.84$ , $P=0.016$ ), high levels of intrusions ( $B=4.11$ , $P=0.019$ ), and hyper-arousal ( $B=8.43$ , $P<0.0005$ ) accounted 51.5% of the variance in PGAC scores.
Mystakidou et al. (2011)	Greece	To investigate the relationship Between, anxiety, PTS, and preparatory grief.	n=94 (M=63.7 years)	<b>-PTS</b> (IES-R-Gr) <b>-Anxiety</b> (Subscale of HADS) <b>-Preparatory Grief</b> (PGAC)	-Significant positive associations were found between IES-R-Gr scales and anxiety: avoidance ( $r=0.433$ , $P<0.0005$ ), intrusion ( $r=0.574$ , $P<0.0005$ ), hyper-arousal ( $r=0.579$ , $P<0.0005$ ). -Anxiety was also positively associated with PGAC ( $r=0.527$ , $P<0.0005$ ). -Sobel test calculations were significant ( $P's<0.0005$ ) indicating that anxiety partially mediated the relationship between each IES-R-Gr scale and PGAC.
Mystakidou , et al. (2012)	Greece	To examine the relationships between PTS, preparatory grief and socio-demographic variables.	n=989 (M=64.41 years)	<b>-Trauma History</b> (SCID- 1 from DSM-IV-TR: The traumatic event screening query from the PTS module). <b>Preparatory Grief</b> (PGAC)	- Participants with PTS were more likely to have metastatic disease ( $P=0.05$ ), be younger ( $P=0.01$ ), and to report higher PGAC scores ( $P=0.003$ ) than those without PTSD.
Udo and Gash (2012)	UK	Case report: intervention for PTS	n=1 female (mid 60s)	<b>-Anxiety and Depression</b> (HADS)	-EMDR, breathing exercises, clinical hypnosis and pharmacotherapy reduced symptoms of PTS and anxiety.

*Centre for Epidemiologic Studies Depression Scale (CES-D); Eastern Co-operative Oncology Group/World Health Organization performance status (ECOG); European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC-QLQ); General Health Questionnaire (GHQ); Hospital Anxiety and Depression Scale (HADS); Hypnotic Induction Profile Scores (HIPS); Impact of Events Scale (IES); Impact of Events Scale-Revised (IES-R), Impact of Events Scale- Revised in Greek (IES-R-Gr); Pittsburg Sleep Quality Index (PSIQ) consisting of a physical (SF-12-PCS) and mental component (SF-12-MCS); Post Traumatic Growth Inventory (PTGI); Preparatory Grief in Advanced Cancer Patients Scale (PGAC); Profile of Mood States (POMS); PTSD Checklist-Civilian Version (PCL-CL); 36 Item Short Form Health Survey (SF-36); 12 Item Short Form Health Survey (SF-12); Structured Clinical Interview for DSM-IV-TR (SCID); Symptom Checklist-90-R (SCL-90-R); Trauma Symptoms Inventory (TSI).*

# **An Exploratory Study into the Traumatic Impact of Advanced Cancer among Patients and Partners**

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## **Abstract**

People living with cancer can experience psychological distress and a sense of personal development. These two responses can be conceptualised within theories of post-traumatic stress (PTS) and post-traumatic growth (PTG) respectively. While much research has been conducted in the area of 'cancer and trauma', there have been relatively fewer studies on individuals with advanced cancer (AC).

*Objective:* This exploratory study investigated the range of experiences of people living with AC and of partners of this group, and considered how theories of PTS and PTG resonated with their accounts.

*Design:* Q-methodology, a technique which combines quantitative and qualitative analysis, was used to examine the participants' subjective experiences.

*Method:* This study was conducted in a hospice setting and used strategic sampling (n=11), gathering data from 8 individuals living with AC and from 3 individuals caring for someone with this diagnosis. Participants rated a set of 62 statements, informed by trauma theories, based on the extent to which these statements resonated with their own personal experience of living with AC, or caring for someone with this illness. The participants were then interviewed about their statement rankings.

*Analysis:* The Q-sort data were subjected to Q-factor analysis. Theories of PTS and PTG were used to aid the interpretation of four differing viewpoints; 'Fearful yet Adapting', 'Accepting and Growing', 'Resigned and Grieving' and 'Traumatised'. The analysis revealed a variety of positive and negative consequences of living with AC.

*Implications:* The findings are of use in clinical practice, as they provide both quantitative and qualitative information on the distress and positive changes experienced in response to AC.

## **Key words**

advanced cancer; post-traumatic stress; post traumatic growth; Q-methodology; adult; partner



## **Introduction**

In 2015, there will be a record two and a half million people living with a diagnosis of cancer (Maddams et al., 2012). Cancer has cost our society approximately £18.3 billion per annum and the National Health Service (NHS) approximately £5 billion (Department of Health & Ellison, 2013). Cancer can have a detrimental impact on an individual's psychological, physical, and interpersonal wellbeing (Brennan, 2004), making research in this area a priority. Due to medical advances, the number of individuals living longer after a diagnosis of both early stage and advanced cancer (AC) is increasing (Low et al., 2007, Maddams et al., 2012), yet those diagnosed with AC have received less attention in the psycho-oncology evidence base.

Individuals with AC are living with the knowledge that their cancer is incurable as it has either metastasised by spreading from its original location to secondary sites (Low et al., 2007), or is based in one location but considered inappropriate for curative treatment (American Cancer Society, 2014). For such individuals, time is precious and professionals are urged to provide high quality holistic care (National Institute of Clinical Excellence, 2004). Care should involve regular "discussion of patients' needs for physical, psychological, social, spiritual, and financial support" (National Institute for Clinical Excellence, 2004, p. 7). Whilst psychological intervention is as important as other forms of intervention in those with AC (Department of Health, 2007), the provision of this 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 et al., 1997). In order to do this, professionals need a sound awareness of the psychological impact of AC.

## **The Psychological Impact of Advanced Cancer (AC)**

The prevalence of psychological problems in those with AC is reportedly high (Irving & Lloyd-Williams, 2010, Kadan-Lottick et al., 2005, van der Lee et al., 2005), with approximately 50% of this population meeting the criteria for having a psychiatric disorder (Miovic & Block, 2007). While

this distress is concerning, to better understand the psychological impact of AC, researchers must also examine the positive changes reported by this population, such as their enhanced appreciation for life (Low et al., 2007).

The positive and negative psychological consequences of cancer are considered in theories which frame illness as a threatening and traumatic event (Brennan, 2001, Joseph & Linley, 2005). Theories on adjusting to traumatic life events, such as cancer, propose that an individual's ability to navigate through life is guided by a mental model of the world (Brennan, 2001, Horowitz, 1986, Joseph & Linley, 2005, Tedeschi & Calhoun, 2004). This model develops in response to an individual's life experiences, and includes beliefs and assumptions about themselves (e.g., I am in control), the world (e.g., the world as safe and just) and their goals (e.g., I will have children). Psychologically shocking events, such as a diagnosis of cancer, challenge this mental model (Brennan, 2001), which generates inner turmoil (Horowitz, 1986). The way in which individuals process and integrate information about the trauma into their existing model can precipitate negative or positive consequences, as manifested through symptoms of post-traumatic Stress (PTS) or post-traumatic Growth (PTG) (Brennan, 2001, Joseph & Linley, 2005).

### **Post-traumatic Stress**

According to the Diagnostic and Statistical Manual of Mental Disorders (DSM-V) (American Psychiatric Association, 2013), individuals who are traumatised report re-experiencing of the traumatic event through nightmares, intrusive memories, or dissociative reactions. They may also try to avoid trauma related thoughts, feelings, or external reminders. Individuals can feel hyper-aroused, angry, scared, numb, or disinterested, and may report disruption to their memory and negative changes in their thinking.

Of the various theories of PTS (Brewin & Holmes, 2003), Horowitz's (1986) Stress Response Theory is dominant in the PTSD literature, and will be used in the present study. Horowitz (1986) proposed that experiences which challenge an individual's mental model cause intense distress. Denial and avoidance are used to protect the individual from the severity of the

traumatic event. However, the individual's innate need to reconcile the incongruence between pre-existing models of the world and trauma-related information means that memories of the event seep into consciousness, causing the trauma to be re-experienced. Processing of the traumatic event occurs in a gradual manner as the individual oscillates between avoidance and re-experiencing of the trauma, steadily amending their mental model to incorporate knowledge gained through the traumatic event. However, excessive use of defences (avoidance and numbness/denial) inhibits processing and trauma-related information may remain in active memory, resulting in PTS (Brewin & Holmes, 2003).

### **Post-traumatic Growth**

While numerous theories of PTG have been published (Janoff-Bulman, 2004, Zoellner & Maercker, 2006), Tedeschi and Calhoun's (2004) model of PTG is the most comprehensive, and will therefore be used in the current study. Tedeschi and Calhoun (2004) define growth as "positive change that occurs as a result of the struggle with highly challenging life crises" (p. 93), which is demonstrated through a greater appreciation for life, more meaningful interpersonal relationships, an enhanced sense of personal strength, altered priorities, and a richer existential and spiritual life; they also emphasise that such growth involves positive changes which are over and above the individual's functioning prior to experiencing the trauma.

Tedeschi and Calhoun (2004) frame traumatic events, such as cancer, as "seismic" (p. 95), challenging a person's beliefs and shattering their mental model of the world. Individuals experience automatic rumination regarding the event, and use various coping strategies to reduce their distress and disengage from previously held beliefs and goals. Subsequent to this, they engage in more effortful and constructive cognitive processing in order to rebuild their mental model. Positive changes in their beliefs (e.g., I am resilient) results in PTG, an enhanced wisdom about life, and a modification of the person's life narrative.

Over the last fifteen years, many researchers have explored the traumatic nature of cancer and confirmed the occurrence of PTS in this

group, manifested as cancer-related intrusions and avoidance of cancer-related stimuli (Gurevich et al., 2002, Jim & Jacobson, 2008, Kangas et al., 2002, Neel, 2000, Smith et al., 1999). Similarly, researchers have also highlighted the presence of PTG in those living with serious medical conditions, such as cancer (Barskova & Oesterreich, 2009, Hefferon et al., 2009, Koutrouli et al., 2012, Parikh et al., 2015). While PTS and PTG in response to early stage cancer has received much attention, there are relatively fewer studies on the traumatic impact of AC.

### **Stress and Growth in Advanced Cancer**

While Akechi et al. (2004) found no incidences of PTS in individuals living with AC, the majority of researchers have identified high levels of traumatic distress in this population. For example, Butler et al. (1999) reported that 52% of women with metastatic breast cancer experienced PTS. Further, in a recent literature review on the traumatic impact of AC (Broderick, F, 2014), high rates of PTS were identified across studies on individuals living with this disease (Kirchheiner et al., 2014, Mystakidou et al., 2012, Posluszny et al., 2011). However, as indicated by theoretical models of adapting to traumatic life events (Brennan, 2001, Joseph et al., 2008), individuals with AC also report PTG (Moore et al., 2011, Mystakidou et al., 2007, Mystakidou et al., 2008). In a qualitative study on the experience of AC (Lethborg et al., 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.

A review of the evidence base also revealed that the partners of those with AC experience PTG (Moore et al., 2011). Similarly, Butler et al. (2005) found that 34% of individuals who were caring for someone with recurrent/metastatic cancer reported clinically significant levels of PTS. However, whilst AC has a traumatic impact on the partners of those with the disease, this group of individuals are largely understudied.

### **The importance of examining stress and growth.**

Research on PTS and PTG in those with AC is necessary and potentially valuable, as PTS can impact on a patient's quality of life (Meisel et al., 2012), suicidality (Spencer et al., 2010), and their willingness to engage in treatment (Udo & Gash, 2012). PTG serves a protective function at a physiological level (Diaz et al., 2014) and is related to enhanced quality of life (Tomich & Helgeson, 2004).

### **Study Rationale**

Researchers (Butler et al., 1999, Meisel et al., 2012, Lethborg et al., 2006, Mystakidou et al., 2007) have suggested that PTS and PTG are important aspects of the way in which people respond to AC. However, the evidence base on the traumatic impact of AC has some limitations. Firstly, there is a paucity of studies which include the partners of those with AC. Secondly, many of the studies are quantitative in nature. Therefore, subjective reports of the individualised experience of AC, and the traumatic impact of the illness are lacking. This means that the applicability of theories of PTS and PTG to the qualitative experience of AC have received limited attention. A Q-methodological study on the experience of people with AC and their partners, considered within the trauma framework would thus be valuable.

### **Study Aims**

This Q-methodology study aimed to explore the range of experiences of individuals living with AC, and the partners of this population. Secondly, it aimed to determine the extent to which theories of PTS and PTG resonate with the true experiences of participants.

### **Method**

Q-methodology was chosen to explore the participants' experiences of AC. The technique combines both quantitative and qualitative analysis (Shabila et al., 2014), exploring the rich subjective viewpoints of participants and arranging them into common factors or stories (Spurgeon et al., 2012). Q-methodology is apt for understanding an individual's experience of illness

and health care (Herron-Marx et al., 2007, Merrick & Farrell, 2012, Rogers, 1991), as it provides insight into “life as lived from the standpoint of the person living it” (Brown, 1996, p. 561). Procedurally, each of the study participants sort a series of ‘statements’ (the Q-set), representative of a range of experiences relating to the impact AC. Participants sort these statements into a distribution of preference (a Q-sort) by considering their level of agreement with each statement. Q-Factor analysis identifies the Q-sorts that are highly correlated with one another, and uncorrelated with others, grouping these Q-sorts into a factor (Watts & Stenner, 2012). The resulting factors are then interpreted to gain insight into participants’ experiences of AC.

### **Design Rationale**

Q-methodology does not seek out dominant themes. Rather, it examines subjectivities and establishes inter-subjectivities (Jeffares & Skelcher, 2011) and so offers a technique to explore the variety of experiences of those with AC. As information on an individual’s experience is gathered from the Q-sort task (Watts & Stenner, 2012), participants were not required to engage in potentially distressing discussion regarding their AC if they did not wish to do so. Q-methodology has been used in previous studies to determine how theoretical models apply to participants viewpoints (Jeffares & Skelcher, 2011). Similarly, this study was interested in how theories of PTS and PTG apply to the viewpoints of individuals encountering AC.

### **Key Methodological Issues**

#### **Reflexivity.**

The lead researcher is a White British, Catholic, middle class female trainee clinical psychologist. She has personal experience of having a degenerative physical health problem and has worked with trauma in a therapeutic capacity. She has volunteered within palliative care services and has no personal experience of living with AC. To mitigate the impact of the researcher’s own perspective upon the research process, both the Q-sort

statement selection and the data analysis were discussed with a second researcher.

### **Ethical considerations.**

The study secured ethical approval from Staffordshire University (Appendix A1), the manager of the hospice where data was collected (Appendix A2), and the NHS research ethics committee (Appendix A3) by the 23rd of April 2014. The researcher aimed to ensure that the study was ethically sound (British Psychological Society, 2009, British Psychological Society, 2010); each participant received a study information pack (Appendix B), provided informed consent (Appendix C) and was debriefed (Appendix D).

### **Designing the Q-set.**

In a Q-study, the concourse, which is the flow of communication encompassing a topic (Brown, 1993), is examined to generate the data gathering tool (the Q-set), which usually comprises 40-70 narrative statements relating to the topic under investigation (Watts & Stenner, 2012).

To examine the concourse on the experience of AC, the researcher used various sources: published literature on PTS and PTG in those with cancer, a four part television documentary on living with AC (Channel 4, 2014), videos featured on cancer support websites (Macmillan Cancer Support, 2014, Novartis Oncology, 2013), and a 60 minute consultation with two experienced nurses. Content analysis (Elo & Kyngas, 2008) was used to code and select statements which reflected the key elements of PTS and PTG theories (Appendix E). This created an initial set of 109 statements. Duplicated statements were then deleted and any similarly phrased statements were merged. This method resulted in a balanced Q-set comprising 62 statements, with 30 related to the positive impacts of AC and 32 related to its negative impacts (Appendix F).

### **Piloting.**

As advised by published guidance (Paige & Morin, 2014) the Q-sort was piloted on a lay person and a health care professional, who were asked

to consider the coverage, clarity, and heterogeneity of statements. Five statements were amended to ensure greater clarity.

### **Participants.**

Within Q-methodology, strategic sampling is used to select participants who are likely to express an interesting or pivotal view point on a topic (Watts & Stenner, 2012). The term AC applies to a heterogeneous group of individuals who have either primary or secondary cancer that is considered incurable (American Cancer Society, 2014). To ensure a clinically homogenous sample, only those living with, or caring for someone, with a diagnosis of secondary cancer were recruited. Participants also had to fulfil the specified inclusion criteria (Table 1).



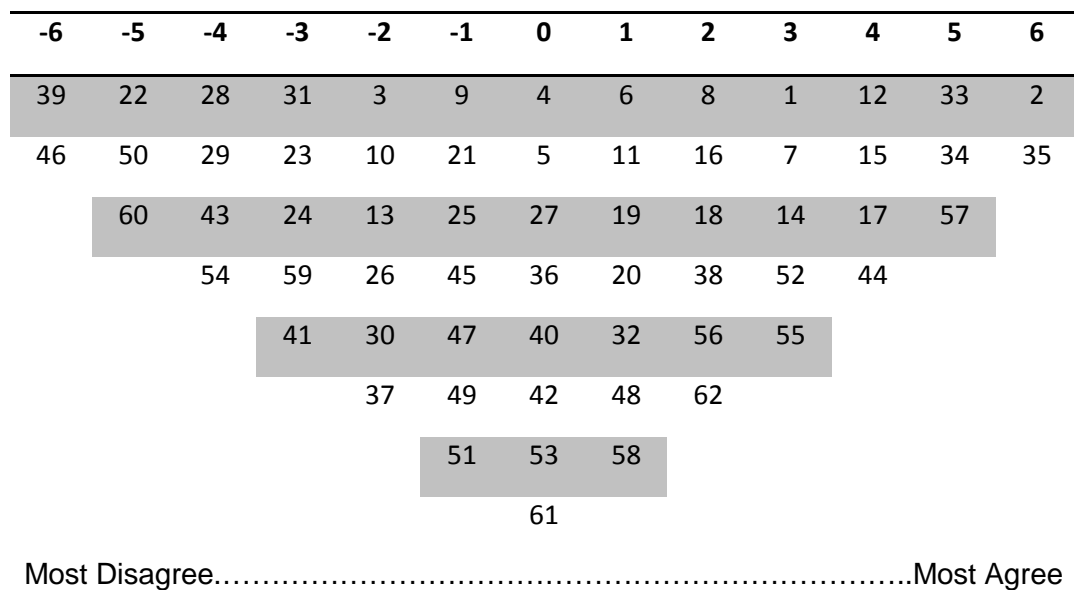
**Table 1: Inclusion Criteria for Study Participation**

Patients Criteria	Partner Criteria
they are aged 18 years and over	they see the person with cancer at least four days a week
they have a diagnosis of secondary cancer i.e. their cancer has metastasised to tissues distant from the original tumour site	they provide emotional and/or practical support to the person with cancer
they are aware that their disease is advanced and deemed incurable	they have known the person with cancer for a minimum of one year
their illness will be life limiting but they will not be deemed to be approaching end of life	they are aged 18 years or over
they may be receiving palliative care treatments, but will not be receiving curative treatments	they are aware that the disease of the person they care for is advanced and deemed incurable
-	the disease of the person they care for will be life limiting, but this person will not be deemed to be approaching end of life
	the person they care for may be receiving palliative care treatments, but will not be receiving curative treatments

Individuals were excluded from the study if they had a cognitive impairment, were imminently approaching end of life, were in-patients in either a hospital or hospice setting, or did not speak English.

**Q-sort task material.**

The final Q-set comprised 62 numbered cards, each printed with a different Q-set statement. A forced choice distribution (Figure 1) was used, in which participants positioned the Q-sort cards on an enlarged Q-sort diagram based on their level of agreement or disagreement with statements (Du Plessis, 2005).



**Figure 1: Example of a Completed Q-sort in the Forced-Choice Distribution**

### Sample size.

Data were collected between October 2014 and April 2015. A total of 8 patients and 3 partners (n=11) completed individual Q-sorts and were interviewed.

### Data collection

Data collection occurred either in the participant's home, or on hospice/hospital premises and took on average 2 hours per participant. Prior to the Q-sort, participants completed a demographics questionnaire (Appendix G). They were also provided with specific instructions to guide their sorting (Figure 2).

**Instructions for Participants with Cancer:** I am interested in how people respond to secondary cancer. I would like you to rate the below statements based on how much you agree with them, whilst considering your **own personal experience** of living with cancer.

**Please rate the statements based on how much you agree with them, from most disagree (+6) through neutral, to most agree (-6)**

**Instructions for Partners:** I am interested in how people respond to secondary cancer. You have experienced secondary cancer by caring for someone with the illness. I would like you to rate the below statements based on how much you agree with them, whilst considering your **own personal experience of providing care** for someone who has cancer.

**Please rate the statements based on how much you agree with them, from most disagree (+6) through neutral, to most agree (-6)**

**Figure 2: Condition of Instruction.**

### **The Q-Sort process.**

The sorting process makes use of the subjective viewpoints of the participants, who impress self-referential meanings onto each Q-statement (McKeown & Thomas, 1988). Participants used the Q-set to model their viewpoints in relation to AC, as the statements were examined, compared, and sorted with reference to their own experiences.

Firstly, participants read the 62 statements and sorted them into three piles; agree, neutral, and disagree. The neutral category was designated for statements to which participants had a neutral or uncertain response. This initial 3 category sorting helps with decision making on the placement of statements along the wider continuum (Stainton Rogers, 1995). Participants were then advised that the statements would be sorted into a normal

distribution from most disagree (-6) to most agree (+6), consistent with the shape of the distribution (Figure 1). Sorting was initiated from the right hand side; taking the agree pile, participants were asked to pick the two statements that they most agreed with, then to select the next three statements that they most agreed with from the remaining statements in this pile. This process was completed until there were no statements left in the agree pile. The researcher then took the disagree pile and asked participants to select the two statements they most disagreed with, then the next three statements they most disagreed with etc. The same process was completed with the neutral pile. The number of each statement and its position was marked onto a blank Q-sort distribution for subsequent analysis.

### **Post- sort interview.**

A post-sort interview was completed in which participants were encouraged to reflect on the personal significance of items that they most agreed with (or disagreed with). Participants were also asked if there were any aspects of their own experience that had not been covered by the Q-set. The qualitative data were recorded and transcribed.

## **Results**

The 62 statements and the participant's data from the 11 Q-sorts were entered into PQmethod software (Schmolck, P., 2014). The aim of the analysis was to interpret a set of meaningful factors, reflecting the range of shared viewpoints of 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). These factors were then scored, interpreted and described (Watts & Stenner, 2012).

### **Participants**

Table 2 presents the demographic information for each participant (n=11). Participant 11 was the partner and carer of participant 4, while participant 2 was the partner and carer of participant 1. The partner of participant 7 did not wish to take part in the study.

**Table 2: Participant Demographic Information**

ID	Gender	Age	Were they living with AC (patient) or caring for someone with AC (partner)?	Had they received psychological therapy?	Location of primary cancer/s?	Date of Diagnosis?
01	F	51-60	Patient	Yes	Colorectal	2007
02	M	51-60	Partner	No	-	2007
03	F	51-60	Patient	Yes	Breast/Bones/liver	2009
04	M	61-70	Patient	Yes	Liver	2012
05	F	41-50	Patient	Yes	Breast	2013
06	F	41-50	Patient	Yes	Breast	2011
07	F	61-70	Partner	No	-	2012
08	F	71-80	Patient	Yes	Breast	2011
09	F	81-90	Patient	No	Breast	2013
10	F	61-70	Patient	Yes	Bowel/Liver	2013
11	F	61-70	Partner	No	-	2012

### Data Analysis

Firstly, a pair-wise correlation matrix (Appendix H) was calculated to identify the level of (dis)similarity between the experience and views of the participants as modelled in their individual Q-sorts (Van Exel & de Graaf, 2005). With regards to the couples within the study, while one couple's (P4 and P11) pair-wise correlation indicated a dissimilar viewpoint ( $r=-0.16$ ,  $p>0.01$ ), the other (P1 and P2) displayed a statistically significant relationship ( $r=0.50$ ,  $p<0.01$ ) which was positive and strong ( $r = \geq 0.5$ ) (Cohen, 1992). This suggests that their views and experiences related to AC were similar.

Centroid factor analysis was employed, which permitted the researcher to explore the data thoroughly and allowed examination of a range of solutions with ease (Watts & Stenner, 2012). Varimax rotation was then used to optimize the separation between factors in order to clarify their structure (Rogers, 1991). Consistent with published guidance (Donner, 2001), the analysis was conducted multiple times, with a different number of factors being extracted and rotated at each trial, with the aim of finding a solution which was sensitive to the variety of viewpoints and statistically appropriate. As demonstrated within the Rotated Factor Matrix (Table 3), this iterative process yielded a final three factor solution which explained

46% of the overall study variance, and accounted for eight out of the eleven Q sorts. This solution was in accordance with published guidance in that each had two or more significant factor loadings ( $r \geq 0.33$ ,  $p < 0.01$ ) and together they explained more than 35-40% of the overall study variance (Brown, 1980, Watts & Stenner, 2012). 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 was also examined. Her Q-sort did not correlate with any of the extracted factors, and therefore represented a unique viewpoint.

**Table 3: Rotated Factor Matrix**

Q-sort	Factor 1	Factor 2	Factor 3
1	0.55*	0.40*	0.14
2	<b>0.47*</b>	0.20	0.26
3	<b>0.47*</b>	0.16	0.32
4	0.12	-0.11	<b>0.38*</b>
5	0.22	0.10	0.15
6	0.48*	0.34*	0.13
7	0.28	0.04	<b>0.73*</b>
8	0.14	<b>0.70*</b>	-0.03
9	0.27	<b>0.58*</b>	-0.03
10	0.25	<b>0.67*</b>	-0.02
11	0.63*	0.33*	0.27
Eigen Value	1.65	1.76	0.99
% var. exp.	<b>15</b>	<b>16</b>	<b>9</b>

**Note** \* indicates a significant correlation ( $r \geq 0.33$ ,  $p < 0.01$ , Brown, 1980). Defining Q-sorts are emboldened.

### Interpretation

During interpretation, the researcher must consider the factors from the perspective of the participants, to gain insight into the story told by each viewpoint (Watts & Stenner, 2012). Q-sorts having a significant loading onto only one factor are thought to define the viewpoint of that factor (Watts & Stenner, 2012), and were therefore used in creating the factor arrays (Appendix I). This is a “snapshot,” of the average sort of individuals within that factor (Donner, 2001). Those Q-sorts that load significantly onto more than one factor are termed ‘confounding Q-sorts’ (P1, P6, and P11) and are not used in creating the factor arrays, as they reflect more than one factor (Watts & Stenner, 2012). Statements ranked at the extreme poles of the

factor array (characterising statements) and statements that were sorted in a significantly different manner in comparison to their ranking on other factors (distinguishing statements) were also used to interpret participants stories (Van Exel & de Graaf, 2005). An account of each factor is provided, supplemented by the rankings of important items (Appendix J), for example (25: -3) means that statement 25 was ranked at the -3 position. The participant's comments, shown in italics, have also been used to aid factor interpretation.

### **Factor One- Fearful but adapting; *how terminal is terminal?***

Factor 1 represented the shared viewpoint of two participants (P2 and P3), one being a male partner (who was caring for P1), and one being a female living with AC.

***Stronger interpersonal relationships.*** These individuals have learned how wonderful people can be and have found that the possibility of death has pulled them closer to people (18: +5, 21: +6). This closeness is manifested in a new willingness to express love; *we always say 'I love you' on the end* (P3). The relationships of these individuals have been saved and strengthened; *we were drifting apart... but I think me having the cancer has brought us a lot closer together* (P3). Individuals sharing this viewpoint feel that the cancer has enhanced their ability to relate to others (60: -5). In particular, P2 viewed himself as learning to become more supportive of his partner; *you learn to be more involved in things.*

***The uncertainty of AC.*** For these individuals the worst part of the experience was finding out that the cancer was incurable (54: +6), as it has left them uncertain 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.*** These individuals reflected on their cognitive efforts to re-appraise cancer as something that they could live with and manage; *you think, right, I've got to go with*

*it... You've got to lift yourself back up, mind, it takes weeks (P2).* They reported feeling anxious when thinking about cancer, being nervous to let out emotion for fear of falling apart, and having felt sad (37: +2, 13: +4, 43: +3). Nevertheless, while these individuals have felt distressed, they have not disengaged from the experience; they were not avoiding thoughts or situations related to cancer, and were not using alcohol or medication to manage their feelings (31: -4, 20: -4, 34: -6). Instead, they were attempting to adapt to their situation, looking for a silver lining and convincing themselves that something good can arise from living with cancer (9: +3, 11: +4). They also rethought how they wished to live their lives (52: 5); *I have changed my priorities in that...if I want something or my children want something...I will spend the money (P3).*

**Factor Two- Accepting and growing; *I don't find cancer frightening.***

Factor 2 represents the shared viewpoint of three participants (P8, P9, P10).

***A new meaning to life.*** Individuals sharing this viewpoint have changed their view on the meaning of life (35: 6). They have spent time evaluating what is important to them and letting go of the things that no longer matter (17: +4). This re-evaluation has also helped them to appreciate the small things in life (57: +5). P10 reflected on the joy she has 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.*

***Strength and coping.*** This outlook has developed a sense of strength through living with cancer. They feel that they have become better people (12, +4) and believe that facing cancer means that they can face future adversity (33, +5). They have developed a range of specific skills which has helped them feel better (2, +6), such as: (a) communicating their 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);* (b) being flexible in encountering change; *It's a case of readapting whatever happens to your body (P8);* (c) 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) and (d) engaging with spiritualism (15, +4). For P8, becoming more spiritual has involved using meditation, and Buddhist 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.*

**Not afraid.** While this outlook found it less distressing than others being diagnosed with an incurable illness (54, -4), these individuals reported being shocked after receiving the initial 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 2 or 3 days that they had made a mistake (P8).* However, their belief in fate means that they are comfortable with the absence of control involved in living with AC; *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).* As a result, these individuals do not feel in immediate danger. Their lives still have meaning, and the future is still important (39, -6; 46, -6).

**Factor Three- Resigned and grieving; *it's taken so much out of the middle of my life.***

Factor 3 represented the shared viewpoint of two participants (P4, P7) one being a female partner, and one being male living with AC.

**Hiding sadness.** For this viewpoint, the experience of cancer has been dominated by a sense of sadness (10, +6; 19, +6). They feel the need to hide this sadness from others, using fake smiles and pretending (10: +6). They do not express this distress as they want to avoid burdening others; *you're fed up enough so why should you inflict your thoughts and feelings on anybody else (P7),* or perhaps because they fear that they would fall apart if they were to express this emotion (43: +3). For P7, her sadness is evoked in watching her husband suffer (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.*

***The cancer experience as a journey of suffering.*** This viewpoint does not view cancer as a gift (32, -6). Their experience has been pervaded by a 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 (P4).* This sense of loss may explain why, behind closed doors, they can get snappy and irritable (36, +4).

They found losing, or witnessing the loss of, physical functioning distressing (3, +5; 51, +2). P4 has found it hard to manage the changes in his body; *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.* These individuals view their body as letting them down as they can no longer engage in hobbies they once enjoyed; *he lost his hobby [singing] when he lost his vocal chords. That was his life (P7).*

This viewpoint has found the cancer to be horrendous, and reported having powerful memories of their experiences (42, +3). In particular, 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.* They have also found it very difficult waiting for the test results (53, +5).

***Acceptance and hopelessness.*** Individuals in this factor are on edge waiting for something awful to happen (39, +4), which is most likely fuelled by their 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 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 awareness has had a positive impact, reinforcing the view that life is not about time spent on this planet, but about what we leave behind (1,+5); *memories are the most important thing you leave behind (P7).* They have evaluated what is important to them in life (17,+4) and are showing 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 also has negative consequences, leaving individuals feeling hopeless and in limbo; *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)*. They are uninspired by stories of other individuals coping (44, -6) and feel hopeless; *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)*.

#### **Viewpoint Four- Traumatized; *It really has been the silent killer.***

This viewpoint was that of a sole participant (P5), a female aged between 41 and 50 years.

**Threat.** For P5, the cancer treatment has been barbaric (40, +6) as it has impacted on 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 discussed the process of adjusting to the knowledge that her illness was incurable, and reflected on how consuming this had been; *I've been so busy thinking about dying that I've forgotten how to live*.

**Distress.** P5 has found the experience distressing, agreeing that it has felt like a rollercoaster, being terrifying and scary (30, +3). She reflected on feeling in constant danger; *you know, the adrenalin is always running around*. This fear means that she avoids things about cancer, particularly on the television (31, +4). She also reported feeling anxious on a daily basis in response to memories of a seizure she experienced which indicated that 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*. She has also experienced periods in which she has felt numb (47, +3), and has doubted whether the cancer was real (62, +3).

Despite feeling distressed, she has learned a lot about how wonderful people can be (18; +6). She feels cared for by those around her (60; -5); *my close friends have been amazing*. The notion of leaving her family who she loves dearly, means that she does not perceive any positive consequences of her cancer and does not see it as a gift (32; -6).

***Finding relief.*** 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 little bit of comfort*. Her heightened distress, and wish for relief means 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*.

### **Consensus statements.**

Consensus statements are those that are sorted similarly across factors (Watts & Stenner, 2012), reflecting agreement between participants. Examination of the consensus statements (Appendix K) suggested that members of Factor One, Two, and Three were not experiencing PTS in response to their AC. They were not experiencing any nightmares (41: -2, -3 -4) or intrusive memories related to their experience (24: -4, -3, -3), and were not using avoidance to manage any distress generated by the illness (31: -4, -4, -3).

### **Did the Q-set adequately represent participants' experiences?**

Ten participants stated that the Q sort was a satisfactory representation of their experience and did not wish to add any additional statements. However, one participant stated that the most difficult component of her experience had been her poor NHS treatment, which she felt unable to communicate through the Q- set. A second participant also reported experiencing poor NHS care, when reflecting on the statement "The treatment is the barbaric bit". Whilst one participant reported being left without food or drink, both reported feeling unsafe, and were upset in

witnessing the care needs of others be neglected; *they'd be calling, nurse...people would just walk past.*

## **Discussion**

This Q-methodology study aimed to explore the range of experiences of individuals with AC, or of caring for someone with this diagnosis. The study identified four viewpoints with differing experiences: 'Fearful yet Adapting', 'Accepting and Growing', 'Resigned and Grieving' and 'Traumatised'. These varying stories support the proposal that an individual's adaptation to cancer and death is highly idiosyncratic (Brennan, 2001, Hall, 2014).

## **Returning to Theory**

The second aim of this study was to determine the applicability of the trauma framework to the experience of living with AC. Accordingly, the stories told by each factor have been considered in relation to theories of PTS and PTG.

Individuals representing Factor One reported being distressed about the uncertainty regarding the time remaining before their own or their partner's death. However, they have re-evaluated how they wish to live life and have experienced stronger and warmer relationships, indicative of PTG (Tedeschi & Calhoun, 2004). An underlying factor in their development of PTG may have been their cognitive efforts in processing their experiences, in that they rethought how they wished to live life and searched for the positive consequences of AC. Those with cancer who engage in positive reappraisal and active cognitive processing, as in our sample, are more likely to experience growth and find meaning in their loss (Bower et al., 1998, Manne et al., 2004, Urcuyo et al., 2005, Sears et al., 2003, Widows et al., 2005). Effortful cognitive processing regarding trauma-related material allows individual's to process and integrate the trauma into their mental model of the world, which is essential in nurturing PTG (Brennan, 2001, Joseph & Linley, 2005, Tedeschi & Calhoun, 2004). Further, while these individuals have developed stronger interpersonal relationships as a consequence of AC,

supportive social networks have also been found to nurture further growth (Cordova et al., 2001, Karanci & Erkam, 2007, Kinsinger et al., 2006, Weiss, 2004). These supportive relationships can provide an outlet for discussing the crisis. They also offer differing perspectives and guidance, which the individual can use in positively rebuilding their views of themselves and the world (Tedeschi & Calhoun, 2004).

Participants representing Factor Two experienced PTG across numerous domains, having an enhanced sense of personal strength, increased spirituality (Tedeschi & Calhoun, 2004) and a new life philosophy (Joseph, 2009). A factor supporting the growth of these individuals may have been their use of specific methods for managing living with cancer, such as expressing one's feelings, adapting to loss, and becoming more spiritual. These coping strategies are both positive and active, in that they are using their own resources to manage a crisis (Zeidner & Endler, 1996). Individuals with cancer who adopt such coping strategies often report greater growth (Bellizzi & Blank, 2006, Kinsinger et al., 2006, Leloir et al., 2010), perhaps because these strategies reduce the individual's level of distress and allow them to engage in constructive cognitive activity to process the trauma (Brennan, 2001), and rebuild their belief system (Tedeschi & Calhoun, 2004). Factor 2 members also appeared to respond to the knowledge and impact of AC in a very flexible manner: *you have to readapt and not think oh this is the end of the world* (P8). This suggests that their pre-existing belief systems may have been flexible, which is associated with better adjustment (Brennan, 2001).

In considering how individuals in Factor One and Two have grown through struggling with AC, it is apt to look for commonalities in their response. In particular, their descriptions of their response to cancer demonstrated that they have "encapsulated" their AC, in that it has not consumed their identity (Nerenz & Leventhal, 1983, cited in Brennan, 2001). This encapsulation allows individuals to continue living life with purpose and meaning, which is associated with better psychological adjustment (Brennan, 2001).

Factor Three cannot be adequately understood through the theories of PTS and PTG. The over-riding theme for this factor is one of sadness, as individuals were reflecting on the losses implicit in AC. P4 is experiencing preparatory grief (Kübler-Ross, 2003), mourning for the pleasures in life that can no longer be, and for the loss of his physical functioning and future opportunities on earth (Moon, 2015). P7's grief differs to P4's, as she is an onlooker to her partner's suffering, and is preparing for the loss of a loved one, a process termed anticipatory grief (Lindemann, 1944). Consistent with Lindemann's (1944) description of anticipatory grieving, P7 has realised that death is inevitable and is experiencing intense sadness, which is "indescribable". She also has an enhanced concern for the dying person [her husband] (Lindemann, 1944), being saddened by the loss of his hobbies and the uncertainty he is facing.

Viewpoint four, represented by P5 reported experiencing hypervigilance, avoidance, and emotions of fear and anger, all of which are indicative of PTS (American Psychiatric Association, 2013). Theories and research into PTS highlight several factors which may underlie her negative experience of AC. Ehlers and Clark (2000) suggest that events are 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 frightening, which has resulted in a state of fear and continual hyper-arousal. Understandably, P5's fear means that she sometimes avoids stimuli related to cancer such as television adverts, and has at times gone into a state of numbness. She also reports excessive rumination regarding "*dying*". These understandable responses (avoidance, numbing, excessive rumination) have all been reported to increase the likelihood of PTS if used excessively (Brennan, 2001), as they prevent adequate processing and integration of trauma-related material (Horowitz, 1986).

### **The applicability of theories of stress and growth to advanced cancer.**

The above descriptions highlight that those living with AC experience a range of positive and negative psychological changes which are consistent

with theories of PTG and PTS. For an event to be deemed traumatic, it must challenge and alter a person's mental model or assumptions about the world (Brennan, 2001, Horowitz, 1986, Tedeschi & Calhoun, 2004). Consistent with this notion, many participants perceived their cancer as having changed their self-perception (*I can cope with anything now* [P10]; *it changes who you are* [P5]), their view of their bodies (*it was growing something...and I thought it was like traitorous* [P6]), and their attitude towards the future (*I try to stay in the moment* [P8]).

Similarly to Akechi et al. (2004), this study's findings contradict prior quantitative studies, which emphasised high levels of PTS in those with AC (Kirchheiner et al., 2014, Mystakidou et al., 2012, Posluszny et al., 2011). As demonstrated by the consensus statements, a number of the Q-sort statements related to PTS were not endorsed by individuals across Factor One, Two and Three. Rather, PTG seemed to be more common in the experiences of these participants. However, the low levels of PTS found in the present study must be considered with caution, as the recruitment process and data collection sites meant that participants may have been less distressed than the general population of individuals with AC. Participants were recruited from a hospice setting in which they were able to receive multi-disciplinary care and psychological therapy. Further, recruiting professionals reported being unable to approach individuals who were "too distressed" by their cancer. Recruiting within the community and enhancing the sample size may have yielded more participants sharing the viewpoint of P5.

In sum, the participants' stories, supplemented by the fact that they generally perceived their Q-sort to be a satisfactory representation of their experience, suggest that theories of PTG and PTS are applicable to living with AC. However, this does not indicate that trauma theories offer more utility than other available theories in understanding the experience of AC. Nor does it suggest that PTG and PTS commonly occur in this group. Instead, this study's findings are valuable in providing descriptive detail of PTG and PTS.



## **Methodological Reflections**

### **Potential confounding factors.**

An individual's distress fluctuates over time as they process trauma-related information (Horowitz, 1982, Tedeschi & Calhoun, 2004). Given this, participants' responses may have been influenced by the length of time since learning of their, or their partner's diagnosis. However, this time period is unknown, as the demographics questionnaire failed to enquire about the specific date that participants had been informed that their, or their partner's cancer, was deemed 'advanced'. Additionally, each interview was completed face-to-face with the participants and it is likely that the researcher's presence will have influenced their responses. However, the interviews were conducted by the same researcher (FB) who attempted to be consistent in their behaviour during the Q-sorting and interview process.

### **Sample size.**

The small sample size of the study ( $n=11$ ) is a limitation. However, Q-methodology does not aim to generalise findings, but simply to establish the existence of varying viewpoints (Brown, 1980). Further, powerful findings can be obtained using a relatively small sample size (Watts & Stenner, 2012). In fact, this study's sample size exceeds that of other Q-methodological studies ( $n=4$ ) and qualitative studies on the experiences of AC (Metzger, 1980; Owens, M. 2010). As this population is difficult to engage in research (Dooley et al., 2010), recruiting and gathering data from 11 individuals is arguably a significant achievement.

### **Strengths and Weaknesses of the Study**

Within Q-methodology, there is a risk of bias at the interpretation stage (Cross, 2005) as the researcher's own perspectives may influence the interpretation of the data (Stainton Rogers, 1995). However, a strength of this study was the researcher's active efforts to minimise the impact of such bias, by witnessing participants complete their Q-sort to ensure a more accurate understanding of their experience, triangulating quantitative and qualitative material, and using multiple researchers to verify the study

conclusions. A key limitation of the study was its failure to provide greater insight into the experiences of the caregivers of those with AC, as only three partners opted to participate in the study. While the responses of partners P2 and P7 have highlighted how caring for someone with AC can result in growth and grief, further exploration of the views of this group is necessary.

## **Clinical Relevance**

### **Implications for practice.**

Findings from this study demonstrate that the experience of AC involves an individualised response, which cannot be described adequately by one over-arching model. This reinforces the notion that professionals should draw on a range of models in providing support for this population. Secondly, two participants reported receiving poor care, with their physiological needs and sense of safety being threatened. In working with care teams, psychologists could use Maslow's (1943) 'hierarchy of needs' to explain the negative implications of failing to meet these fundamental needs. Thirdly, individuals with AC should be encouraged to use active coping strategies and engage in effortful reflection, as findings from this study and from other researchers (Bellizzi & Blank, 2006, Bower et al., 1998, Kinsinger et al., 2006, Leloirain et al., 2010) suggest that these responses may nurture growth. 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, 1982). Most importantly, the results of this study highlight the resilience of the human spirit, and remind professionals to remain aware of the potential for positive change in the face of AC.

### **Implications for research.**

There are a number of implications for researchers. Firstly, this study is evidence of the applicability of Q-methodology for future investigations within this population. Participants reported that the Q-sort process promoted careful discussion of emotive topics and positive reflection; P8 relayed that completing the Q-sort had helped her identify the positive ways in which she

has managed her AC. This is encouraging, as helping individuals to recognise and define the positive consequences of difficult life events is thought to nurture more growth (Joseph & Linley, 2005). However, the approach was deemed inaccessible for individuals who were “too distressed”, meaning that the more negative consequences of AC may still remain unexplored. Future research could therefore involve recruiting palliative care professionals to complete a Q-sort from the perspective of a specific patient with AC, to share their professional insights on the distress experienced by individuals with AC who are unable to participate. Asking participants to sort Q-items from another person's perspective is not uncommon in Q-methodology (Stephenson, 1979).

## **Conclusion**

While having certain limitations, this study has nonetheless provided insight into the various ‘versions of reality’ (Rogers, 1991, p.127) experienced by individuals living with or caring for someone with AC. The study has demonstrated that the knowledge of impending death can precipitate both positive and negative changes within the individual. It has also highlighted that theories of PTG and PTS may pose some utility in understanding the experiences of this group, and recommends further investigation with participants outside of hospice settings.

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## Appendices

### Appendix A: Documentation of Ethical Approvals

#### Appendix A1- Ethical approval from Staffordshire University



**STAFFORDSHIRE  
UNIVERSITY**

Faculty of Computing,  
Engineering and Sciences

Staffordshire University  
The Science Centre  
Leek Road  
Stoke-on-Trent ST4 2DF  
United Kingdom

+44 (0) 1782 294000 (enquiries)  
+44 (0) 1782 294573 (direct)  
sciencesawardadmin@staffs.ac.uk  
www.staffs.ac.uk

Date: 11<sup>th</sup> March 2014

To whom it may concern

**Application for Independent Peer Review Approval**

**Researcher:** Fiona Broderick  
**Study Title:** Living with Secondary Cancer: the role of post-traumatic stress (PTS) and post traumatic growth (PTG)

I can confirm that Staffordshire University supports this research project proposal being put forward by the above research project applicant, and that the University is willing to act as sponsor of the project if it received LREC approval.

Our support for this project takes account of the outcome of an independent peer review of its scientific merit undertaking within the University.

I can also confirm that the University has generic indemnity/insurance arrangements in place as stated on the attachment to this letter, that arrangements will be in place before the study starts for the research team to access resources and support to deliver the research as proposed, that arrangements to allocate responsibilities for the management, monitoring and reporting of the research will be in place before the research starts and that the duties of sponsors set out in the NHS Research Governance Framework for Health and Social Care will be undertaken in relation to this research.

  
Professor Nachiappan Chockalingam  
Chair,  
University Academic Ethics Sub-Committee

■ CREATE THE DIFFERENCE

  
INVESTOR IN PEOPLE

## Appendix A2- Hospice ethical approval.



Severn Hospice

Apley Castle  
Telford  
TF1 6RH

Tel: 01952 221 350  
Fax: 01952 221 360

Dear Sir/Madam,

I confirm that the researcher has permission to implement the following research project at Severn Hospices.

**Title of the research:** Living with Secondary Cancer: the role of post-traumatic stress (PTS) and post traumatic growth (PTG).

**Researchers name:** Fiona Broderick (Trainee Clinical Psychologist)

**Organisation:** Staffordshire and Keele Universities

**Site Supervisor:** Dr Marilyn Owens  
(Macmillan Consultant Clinical Psychologist)

I am aware that this will involve recruitment of service users to participate in the study, and I give permission for the researcher to visit the hospices to discuss the research with other professionals and potential participants. Further, I understand that the research may at times be carried out on site, dependent upon where participants chose to complete their interview.

A copy of the research proposal has been given to me by the researcher. The researcher has also agreed that in the event of the research being published, both the name of the hospice and my own name will be mentioned within the publication.

Yours faithfully,

Dr Derek Willis  
Palliative Care Consultant Severn Hospice (Telford)  
MRCP MBChB (Hons)JCGPTE MSc Dip Clin Ed

## Appendix A3- NHS ethical approval.



### NRES Committee South Central - Berkshire B

Bristol REC Centre  
Whitefriars  
Level 3, Block B  
Lewins Mead  
Bristol  
BS1 2NT

Telephone: 01173421331 Facsimile: 01173420445 23 April 2014

Miss Fiona Elizabeth Broderick  
Faculty of Health Sciences  
Science Centre, Staffordshire University  
Leek Road, Stafford  
ST4 2DF

Dear Miss Broderick

**Study title:** Living with Secondary Cancer: the role of post-traumatic stress (PTS) and post-traumatic growth (PTG).  
**REC reference:** 14/SC/0239  
**Protocol number:** N/A  
**IRAS project ID:** 146722

Thank you for your letter of 23 April 2014. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 22 April 2014

#### Documents received

The documents received were as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering Letter		23 April 2014
Other: Severn Hospice Approval		
Other: Appendix K- Written debrief - complete sorting task	2	23 April 2014

Questionnaire: Appendix J- Questionnaire Schedule	2	23 April 2014
Other: Appendix L- Written debrief - did not complete sorting task	2	23 April 2014
Participant Information Sheet: Appendix B - Information Sheet Health Professionals	2	23 April 2014
Participant Information Sheet: Appendix E - Information Sheet patients with secondary care	2	23 April 2014
Participant Information Sheet: Appendix F- Information Sheet Partners	2	23 April 2014
Protocol	2	23 April 2014

### Approved documents

The final list of approved documentation for the study is therefore as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering Letter		23 April 2014
Evidence of insurance or indemnity	Appendix Q	
Investigator CV	Academic Supervisor 1 - Helen Combes	
Investigator CV	Chief Investigator - Fiona Broderick	
Letter of invitation to participant	Potential Participants with Secondary Cancer - Appendix C - 1	12 April 2014
Letter of invitation to participant	Partners - Appendix D - 1	12 April 2014
Other: Demographics Sheet	Appendix I - 1	12 April 2014
Other: Research Contract	Appendix M - 1	12 April 2014
Other: Email from Fiona Broderick		15 April 2014
Other: Severn Hospice Approval		
Other: Appendix K- Written debrief - complete sorting task	2	23 April 2014
Other: Appendix L- Written debrief - did not complete sorting task	2	23 April 2014

Participant Consent Form: Individuals with Secondary Cancer	Appendix G - 1	12 April 2014
Participant Consent Form: Partners	Appendix H - 1	12 April 2014
Participant Information Sheet: Appendix B - Information Sheet Health Professionals	2	23 April 2014
Participant Information Sheet: Appendix E - Information Sheet patients with secondary care	2	23 April 2014
Participant Information Sheet: Appendix F- Information Sheet Partners	2	23 April 2014
Protocol	2	23 April 2014
Questionnaire: Appendix J- Questionnaire Schedule	2	23 April 2014
REC application		14 April 2014
Referees or other scientific critique report	Guidance from the	12 April 2014
	Independent Peer Review - Appendix N	
Referees or other scientific critique report	Independent Peer Review - Appendix P	12 April 2014
Referees or other scientific critique report	Letter to Chair - Appendix O - 1	12 April 2014
Summary/Synopsis	Flowchart for Participation in the Study - Appendix A - 1	12 April 2014

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

<b>14/SC/0239</b>	<b>Please quote this number on all correspondence</b>
-------------------	---

Yours sincerely



Miss Stephanie Macpherson REC Manager

E-mail: [nrescommittee.southcentral-berkshireb@nhs.net](mailto:nrescommittee.southcentral-berkshireb@nhs.net)

Copy to: Dr Helen Combes, Staffordshire University [h.a.combes@staffs.ac.uk](mailto:h.a.combes@staffs.ac.uk)

Ms Audrey Bright, South Staffordshire and Shropshire Healthcare NHS Foundation Trust  
audrey.bright@sssft.nhs.uk

## **Appendix B: Participant Information Packs**

### **Appendix B1- Information pack for person with cancer.**

## **Staffordshire & Keele Universities**

### **Doctorate in Clinical Psychology**

#### **DClinPsy**

Faculty of Health Sciences, Staffordshire University,  
Leek Road, Stoke-on-Trent ST4 2DF  
E [DClinPsy@staffs.ac.uk](mailto:DClinPsy@staffs.ac.uk)  
T +44 (0)1782 - 294007  
W <http://www.staffs.ac.uk>



Dear sir/madam,

My name is Fiona Broderick. I am a Trainee Clinical Psychologist working within South Staffordshire. I am writing to invite you to take part in a research study. I am carrying out the study as part of the Professional Doctorate in Clinical Psychology at Staffordshire University.

Scientific literature suggests that the experience of living with a complex illness (like secondary cancer) is traumatic and can have a dramatic impact on a person's life. I am interested in exploring this topic. The aim of the study is to learn more about the opinions of people who have secondary cancer. I will also be looking at the opinions of the partners of those with secondary cancer. I wish to develop our current understanding of a person's response to this illness. There are two aspects of this response that I am interested in. Literature says that people living with cancer experience great distress in response to the illness, but also find that they discover some benefits to having the illness; they have a new perspective on life.

Research already available on this topic focuses very little on the true views of the people living with secondary cancer. I hope to be able to add to the research base, communicating the views and voices of those with cancer. Findings from the study should increase our understanding of the healthcare needs of people with secondary cancer and their partners.

The research has been approved by Staffordshire University Peer Review Panel and by a Research Ethics Committee.



I have enclosed an information sheet about the study. If you think you might be interested in taking part and would like to find out more, please complete the slip at the bottom of this page. Please return it to the health care professional that gave you the research pack, or post it using the pre-paid envelope. I will then contact you to discuss the study and see whether you would like to be involved. By returning this form you are not committing yourself to taking part.

I hope that you will be interested in finding out more and I look forward to hearing from you.

Many thanks and best wishes,

Fiona Broderick  
Trainee Clinical Psychologist

Fiona Broderick (Trainee Clinical Psychologist)  
Contact Address: Clinical Psychology Professional Doctorate  
Faculty of Health Sciences - Science Centre  
Staffordshire University  
Leek Road  
Stoke-on-Trent  
ST4 2DF  
Contact Telephone number- t: 01782 294007 f: 01782 295785  
Contact E-mail: b027439b@student.staffs.ac.uk

### OPT-IN SLIP

-----

I would like to know more about the study exploring people's experiences of secondary cancer.

Name \_\_\_\_\_

Address \_\_\_\_\_

How would you like to be contacted? telephone/email (Please delete as appropriate)

Please provide the necessary contact details

Telephone Number \_\_\_\_\_

Email address \_\_\_\_\_

# Staffordshire & Keele Universities

## Doctorate in Clinical Psychology

### DClinPsy

Faculty of Health Sciences, Staffordshire University,

Leek Road, Stoke-on-Trent ST4 2DF

E [DClinPsy@staffs.ac.uk](mailto:DClinPsy@staffs.ac.uk)

T +44 (0)1782 - 294007

W <http://www.staffs.ac.uk>



Keele University

### Study Title

#### **Living with secondary cancer: the role of post-traumatic stress (PTS) and post traumatic growth (PTG)**

You are being invited to take part in a research study. Before you decide whether you would like to take part it is important that you understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish. Do not hesitate to contact me if there is anything that is not clear to you or if you would like more information. Please take time to decide whether or not you wish to take part.

### **Thank you for reading this!**

### **What is the purpose of the study?**

The aim of the study is to learn more about the opinions of people who have secondary cancer and their partners. Specifically, I wish to develop our current understanding of a person's response to secondary cancer. There are two aspects to the response that I am interested in. I wish to look at how this experience can be traumatic on one hand, but how it can cause a person to gain a new appreciation for life on the other; the person is said to 'grow'. My hope is that this will help to increase our understanding of the support and healthcare needs of people with secondary cancer.

### **Why have I been chosen?**

You have been chosen because your health care team has identified you as someone with a diagnosis of Secondary Cancer who could make a valuable contribution to this study.

### **Do I have to take Part?**

No. It is up to you to decide whether or not to take part. If you do decide to take part you will be asked to sign a consent form. After signing the form, you are still free to withdraw from the study at any stage, up until the research is submitted for publication. You do not have to give any reason for wishing to withdraw. A decision to withdraw at any time, or a decision not to take part, will not have any effect on your treatment or care.

### **What will happen to me if I take part?**

If you decide to take part, the researcher will call you to arrange a convenient time and place to meet with you. This can be at a location that is convenient for you. The researcher will firstly have a short discussion with you about your understanding of the study and will collect some basic demographic information from you. There will be one card sorting task, in which the researcher will ask you to sort a small pile of cards dependent on how much you agree with the statements on the cards. After this, there is opportunity for a short discussion about the task which will take place with the researcher. This conversation will be audiotaped to ensure that the researcher has an accurate record of your feedback. After your participation, the tape will be transcribed and coded so that all the information is confidential. All other information you provide will be neatly documented and anonymised.

During your participation, you are free to choose to disengage from the task, or to avoid answering any questions that arise. You will also be given the opportunity to ask any questions that you might have.

Prior to starting the task you will also be asked whether you give consent for your feedback and your quotations to be used from your short discussion. The researcher will ask you to sign a consent form. You will also be asked whether you give consent for the researcher to use the information that you have provided in the event that your health deteriorates and you are not able to comment on the write-up of the study.

### **What are the possible disadvantages of taking part?**

Reflecting upon your experiences may raise issues which you have not talked about before, or which may be upsetting to you. You will be under no pressure to complete the task within the study or to talk about anything you do not wish to. You are also able to access psychological support prior to, during, and after your participation in the study using the contacts below:

- 1) Dr Marilyn Owens  
Macmillan Consultant Clinical Psychologist  
Severn Hospice  
Apley Castle  
Telford  
TF1 6RH  
Tel: 01952 221350  
Fax: 01952 221360

Dr Marilyn Owens will support you to access specialist psychological support in cancer and palliative care at Severn hospice. Please feel free to contact her via writing or telephone.

- 2) The Hamar Help and Support Centre

Royal Shrewsbury Hospital  
Mytton Oak Road  
Shrewsbury  
SY3 8XQ  
Tel: 01743261035  
Fax: 0174361465  
E-mail: [hamarcentre@sath.nhs.uk](mailto:hamarcentre@sath.nhs.uk)

Please feel free to telephone or 'drop-in' to the Hamar Centre for general information, or to book an appointment for psychological support. The centre is open 9.00am to 5.00pm Monday to Friday

- 3) You can also contact your General Practitioner (GP) who will be able to refer you onto the appropriate services.

Further, if you are unhappy about any aspect of the way you have been approached or treated during the course of the study, you may contact my supervisor:

Dr Helen Combes  
Clinical Lecturer and Chartered Clinical Psychologist  
Staffordshire University  
Clinical Psychology Professional Doctorate  
Faculty of Health Sciences - Science Centre  
Staffordshire University  
Leek Road  
Stoke-on-Trent  
ST4 2DF  
Contact Telephone number- **t:** 01782 294007 **f:** 01782 295785  
Contact E-mail: [H.A.Combes@staffs.ac.uk](mailto:H.A.Combes@staffs.ac.uk)

### **What are the possible advantages of taking part?**

We cannot promise that the study will help you, but the information we get from this study will help improve the psychological treatment of people with secondary cancer. Ultimately, the study will provide insight into the real views of those that experience secondary cancer and their partners. This will help health care professionals to have more insight into how to support these individuals.

### **Will my taking part in this study be kept confidential?**

Yes. All information in this study will be kept confidential. The researcher will conduct the study according to the Data Protection Act (1988). Any information about you will be coded so that you cannot be identified. All information will be kept in files or on secure memory sticks in a locked filing cabinet. After the study, the data will be kept for 5 years at Staffordshire University.

It is necessary to mention that there are limits to this confidentiality. If you provide information that indicates that you or anyone else close to you is at risk of harm, the researcher will have to discuss this information with their research supervisors. Please ask for more information on this if you have any questions.

### **What will happen to the results of this research study?**

The research is part of a professional doctoral thesis and will be completed by September 2015. The research will be sent for publication to a scientific journal.

**Who is organising and funding the research?**

The researcher is carrying out the study for the Professional Doctorate in Clinical Psychology at Staffordshire and Keele Universities.

**Who has reviewed the study?**

The study has been reviewed by Staffordshire University Peer Review Panel and by a Research Ethics Committee.

**Who can I contact for further information?**

If you would like any further information about the study, or have any questions, please do not hesitate to contact me: Fiona Broderick

Contact Address: Clinical Psychology Professional Doctorate  
Faculty of Health Sciences - Science Centre  
Staffordshire University  
Leek Road  
Stoke-on-Trent  
ST4 2DF

Contact Telephone number- t: 01782 294007 f: 01782 295785

Contact E-mail: b027439b@student.staffs.ac.uk

Alternatively, if you have any cause for concern about this research, please contact my supervisor:

Dr Helen Combes  
Clinical Lecturer and Chartered Clinical Psychologist  
Staffordshire University  
Clinical Psychology Professional Doctorate  
Faculty of Health Sciences - Science Centre  
Staffordshire University  
Leek Road  
Stoke-on-Trent  
ST4 2DF

Contact Telephone number- **t:** 01782 294007 **f:** 01782 295785

Contact E-mail: H.A.Combes@staffs.ac.uk

OR

You can contact Patient Advice Liaison Service (PALS) via the following routes:  
Telephone number- 01785 783028. The line is open between 9.00 am – 5.00 pm  
Monday to Friday. Alternatively, you can email the PALS Co-ordinator –  
[pals@sssft.nhs.uk](mailto:pals@sssft.nhs.uk)

**Thank you for your interest in this study!**

## Appendix B2- Information pack for partners.

# Staffordshire & Keele Universities

## Doctorate in Clinical Psychology

### DClinPsy

Faculty of Health Sciences, Staffordshire University,  
Leek Road, Stoke-on-Trent ST4 2DF

E [DClinPsy@staffs.ac.uk](mailto:DClinPsy@staffs.ac.uk)

T +44 (0)1782 - 294007

W <http://www.staffs.ac.uk>



Dear sir/madam,

My name is Fiona Broderick. I am a Trainee Clinical Psychologist working within South Staffordshire. I am writing to invite you to take part in a research study. I am carrying out the study as part of the Professional Doctorate in Clinical Psychology at Staffordshire University.

Scientific literature suggests that the experience of living with a complex illness (like secondary cancer) is traumatic and can have a dramatic impact on a person's life. I am interested in exploring this topic. The aim of the study is to learn more about the opinions of the partners of people with secondary cancer. The term 'partner' relates to anyone that provides emotional or practical support to someone with secondary cancer, and who sees this person at least four times a week. I will also be looking at the opinions of those with secondary cancer. I wish to develop our current understanding of a person's response to this illness. There are two aspects of this response that I am interested in. Literature says that people living with cancer experience great distress in response to the illness, but also find that they discover some benefits to having the illness; they have a new perspective on life.

Research already available on this topic focuses very little on the views of the partners of those with secondary cancer. I hope to be able to add to the

research base, communicating the views and voices of these people. Findings from the study should increase our understanding of the healthcare needs of people with secondary cancer and their partners.

The research has been approved by Staffordshire University Peer Review Panel and by a Research Ethics Committee.

I have enclosed an information sheet about the study. If you think you might be interested in taking part and would like to find out more, please complete the slip at the bottom of this page. Please return it to the health care professional that gave you the research pack, or post it using the pre-paid envelope. I will then contact you to discuss the study and see whether you would like to be involved. By returning this form you are not committing yourself to taking part.

I hope that you will be interested in finding out more and I look forward to hearing from you.

Many thanks and best wishes,

Fiona Broderick  
Trainee Clinical Psychologist

<p>Fiona Broderick (Trainee Clinical Psychologist) Contact Address: Clinical Psychology Professional Doctorate Faculty of Health Sciences - Science Centre Staffordshire University Leek Road Stoke-on-Trent ST4 2DF Contact Telephone number- t: 01782 294007 f: 01782 295785 Contact E-mail: b027439b@student.staffs.ac.uk</p>
--

### OPT-IN SLIP

-----  
I would like to know more about the study exploring people's experiences of secondary cancer.

Name \_\_\_\_\_

Address \_\_\_\_\_

How would you like to be contacted? telephone/email (Please delete as appropriate)

Please provide the necessary contact details  
Telephone Number \_\_\_\_\_  
Email address \_\_\_\_\_

## Staffordshire & Keele Universities

### Doctorate in Clinical Psychology

#### DClinPsy

Faculty of Health Sciences, Staffordshire University,  
Leek Road, Stoke-on-Trent ST4 2DF  
E [DClinPsy@staffs.ac.uk](mailto:DClinPsy@staffs.ac.uk)  
T +44 (0)1782 - 294007  
W <http://www.staffs.ac.uk>



Keele University

#### Study Title

#### **Living with secondary cancer: the role of post-traumatic stress (PTS) and post traumatic growth (PTG)**

You are being invited to take part in a research study. Before you decide whether you would like to take part it is important that you understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish. Do not hesitate to contact me if there is anything that is not clear to you or if you would like more information. Please take time to decide whether you wish to take part.

#### **Thank you for reading this!**

#### **What is the purpose of the study?**

The aim of the study is to learn more about the opinions of people who have secondary cancer and their partners. Specifically, I wish to develop our current understanding of a person's response to secondary cancer. There are two aspects to the response that I am interested in. I wish to look at how this experience can be traumatic on one hand, but how it can cause a person to gain a new appreciation for life on the other; the person is said to 'grow'. My hope is that this will help to increase our understanding of the support and healthcare needs of people with secondary cancer, and their partners.

#### **Why have I been chosen?**

A health care professional has identified you as being a family member or carer to someone with a diagnosis of Secondary Cancer, and as someone who could make a valuable contribution to this study.

#### **Do I have to take Part?**

No. It is up to you to decide whether or not to take part. If you do decide to take part, you will be asked to sign a consent form. After signing the form, you are still



free to withdraw from the study up until the research is submitted for publication. You do not have to give any reason for wishing to withdraw. A decision to withdraw at any time, or a decision not to take part, will not have any effect on your (or your partner's) treatment or care.

### **What will happen to me if I take part?**

If you decide to take part, the researcher will call you to arrange a convenient time and place to meet with you. This can be at a location that is convenient for you. The researcher will firstly have a short discussion with you about your understanding of the study and will collect some basic demographic information from you. There will be one card-sorting task, in which the researcher will ask you to sort a small pile of cards dependent on how much you agree with the statements on the cards. After this, there is opportunity for a short discussion about the task, which will take place with the researcher. This conversation will be audiotaped to ensure that the researcher has an accurate record of your feedback. After your participation, the tape will be transcribed and coded so that all the information is confidential. All other information you provide will be neatly documented and anonymised.

During your participation, you are free to choose to disengage from the task, or to avoid answering any questions that arise. You will also be given the opportunity to ask any questions that you might have. Prior to starting the task you will also be asked whether you give consent for your feedback and your quotations to be used from your short discussion. The researcher will ask you to sign a consent form.

### **What are the possible disadvantages of taking part?**

Reflecting upon your experiences may raise issues that you have not talked about before, or which may be upsetting to you. You will be under no pressure to complete the task within the study, or to talk about any topics you wish to avoid. You are also able to access psychological support prior to, during, and after your participation in the study using the contacts below:

- 1) Dr Marilyn Owens  
Macmillan Consultant Clinical Psychologist  
Severn Hospice  
Apley Castle  
Telford  
TF1 6RH  
Tel: 01952 221350  
Fax: 01952 221360

Dr Marilyn Owens will support you to access specialist psychological support in cancer and palliative care at Severn hospice. Please feel free to contact her via writing or telephone.

- 2) The Hamar Help and Support Centre  
Royal Shrewsbury Hospital  
Mytton Oak Road  
Shrewsbury  
SY3 8XQ  
Tel: 01743261035

Fax: 01743261465

Email: [hamarcentre@sath.nhs.uk](mailto:hamarcentre@sath.nhs.uk)

Please feel free to telephone or 'drop-in' to the Hamar Centre for general information, or to book an appointment for psychological support. The centre is open 9.00am to 5.00pm, Monday to Friday.

You can also contact your General Practitioner (GP) who will be able to refer you onto the appropriate services.

Further, if you are unhappy about any aspect of the way you have been approached or treated during the course of the study, you may contact my supervisor:

Dr Helen Combes

Clinical Lecturer and Chartered Clinical Psychologist

Staffordshire University

Clinical Psychology Professional Doctorate

Faculty of Health Sciences - Science Centre

Staffordshire University

Leek Road

Stoke-on-Trent

ST4 2DF

Contact Telephone number- t: 01782 294007 f: 01782 295785

Contact E-mail: [H.A.Combes@staffs.ac.uk](mailto:H.A.Combes@staffs.ac.uk)

### **What are the possible advantages of taking part?**

We cannot promise that the study will help you, but the information we get from this study will help improve the psychological treatment of people with secondary cancer. Ultimately, the study will provide insight into the real views of those that experience secondary cancer and their partners. This will help health care professionals to have more insight into how to support these individuals.

### **Will my taking part in this study be kept confidential?**

Yes. All information in this study will be kept confidential. The researcher will conduct the study according to the Data Protection Act (1988). Any information about you will be coded so that you cannot be identified. All information will be kept in files or on secure memory sticks in a locked filing cabinet. After the study, the data will be kept for 5 years at Staffordshire University.

It is necessary to mention that there are limits to this confidentiality. If you provide information that indicates that you or anyone else close to you is at risk of harm, the researcher will have to discuss this information with their research supervisors. Please ask for more information on this if you have any questions.

### **What will happen to the results of this research study?**

The research is part of a professional doctoral thesis and will be completed by September 2015. The research will be sent for publication to a scientific journal.

### **Who is organising and funding the research?**

The researcher is carrying out the study for the Professional Doctorate in Clinical Psychology at Staffordshire and Keele Universities.

### **Who has reviewed the study?**

The study has been reviewed by Staffordshire University Peer Review Panel and by a Research Ethics Committee.

**Who can I contact for further information?**

If you would like any further information about the study, or have any questions, please do not hesitate to contact me: Fiona Broderick

Contact Address: Clinical Psychology Professional Doctorate  
Faculty of Health Sciences - Science Centre  
Staffordshire University  
Leek Road  
Stoke-on-Trent  
ST4 2DF

Contact Telephone number- t: 01782 294007 f: 01782 295785

Contact E-mail: [b027439b@student.staffs.ac.uk](mailto:b027439b@student.staffs.ac.uk)

Alternatively, if you have any cause for concern about this research, please contact my research supervisor:

Dr Helen Combes  
Staffordshire University  
Clinical Psychology Professional Doctorate  
Faculty of Health Sciences - Science Centre  
Staffordshire University  
Leek Road  
Stoke-on-Trent  
ST4 2DF

Contact Telephone number- t: 01782 294007 f: 01782 295785

Contact E-mail: [H.A.Combes@staffs.ac.uk](mailto:H.A.Combes@staffs.ac.uk)

**OR**

You can contact Patient Advice Liaison Service (PALS) via the following routes:  
Telephone number- 01785 783028. The line is open between 9.00 am – 5.00 pm  
Monday to Friday. Alternatively, you can email the PALS Co-ordinator –

[pals@sssft.nhs.uk](mailto:pals@sssft.nhs.uk)

Thank you for your interest in this study!

## Appendix C: Consent

### Appendix C1- Consent for individuals with cancer.

## Staffordshire & Keele Universities

## Doctorate in Clinical Psychology

### DClinPsy

Faculty of Health Sciences, Staffordshire University,

Leek Road, Stoke-on-Trent ST4 2DF

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T +44 (0)1782 - 294007

W <http://www.staffs.ac.uk>



Keele University

### **Living with secondary cancer: the role of post-traumatic stress (PTS) and post traumatic growth (PTG).**

Name of Researcher and contact details:

Fiona Broderick (Trainee Clinical Psychologist)

Contact Address: Clinical Psychology Professional Doctorate  
Faculty of Health Sciences - Science Centre  
Staffordshire University  
Leek Road  
Stoke-on-Trent  
ST4 2DF

Contact Telephone number- t: 01782 294007 f: 01782 295785

Contact E-mail: [b027439b@student.staffs.ac.uk](mailto:b027439b@student.staffs.ac.uk)

1. I confirm that I have read and understood the information sheet for the above study. I have had the opportunity to consider the information and to ask questions, and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw up until the research is submitted for publication, without my legal or medical rights being affected. ☐
3. I agree to have my feedback in the short discussion with the researcher audio-recorded. ☐
4. I agree that the information I provide within the study (my responses) can be used for the purposes of research and publication, and that any quotations from this research can be used in the write-up and publication. ☐

5. I agree that the information I provide within the study (my responses) can be used for the purposes of research and publication in the event that my health deteriorates and I am unable to provide feedback on the write up of the study. ☐
6. I agree for my data to be seen by NHS and University Regulatory bodies. ☐
5. I agree to take part in the above study. ☐

Name of Participant  
Date

Signature

Name of Researcher  
Date

Signature

## Appendix C2- Consent for partners.

# Staffordshire & Keele Universities

## Doctorate in Clinical Psychology

### DClinPsy

Faculty of Health Sciences, Staffordshire University,  
Leek Road, Stoke-on-Trent ST4 2DF  
E [DClinPsy@staffs.ac.uk](mailto:DClinPsy@staffs.ac.uk)  
T +44 (0)1782 - 294007  
W <http://www.staffs.ac.uk>



### Living with secondary cancer: the role of post-traumatic stress (PTS) and post traumatic growth (PTG)

Name of Researcher and contact details:

Fiona Broderick (Trainee Clinical Psychologist)  
Contact Address: Clinical Psychology Professional Doctorate  
Faculty of Health Sciences - Science Centre  
Staffordshire University  
Leek Road  
Stoke-on-Trent  
ST4 2DF  
Contact Telephone number- t: 01782 294007 f: 01782 295785  
Contact E-mail: b027439b@student.staffs.ac.uk

1. I confirm that I have read and understood the information sheet for the above study. I have had the opportunity to consider the information and to ask questions, and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw up until the research is submitted for publication, without mine or my partner's legal or medical rights being affected. ☐
3. I agree to have my feedback in the short discussion with the researcher audio-recorded. ☐

4. I agree that the information I provide within the study (my responses) can be used for the purposes of research and publication, and that any quotations from this research can be used in the write-up and publication of the study.

☐

5. I agree for my data to be seen by NHS and University Regulatory bodies.

☐

6. I agree to take part in the above study.

☐

Name of Participant  
Date

Signature

Name of Researcher  
Date

Signature

## Appendix D: Debrief

### Appendix D1- Debrief for those who did not complete the study.

## Staffordshire & Keele Universities

### Doctorate in Clinical Psychology

#### DClinPsy

Faculty of Health Sciences, Staffordshire University,  
Leek Road, Stoke-on-Trent ST4 2DF  
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T +44 (0)1782 - 294007  
W <http://www.staffs.ac.uk>



Thank you for taking part in the following study titled:

#### **Living with secondary cancer: the role of post-traumatic stress (PTS) and post traumatic growth (PTG).**

Your input and effort has been much appreciated! We would like to assure you that any data you have provided will be destroyed, and that your withdrawal from the study will have no impact on your (or your partner's) treatment and care.

I would like to emphasise that if you are unhappy about any aspect of the way you have been approached or treated during the course of the study, you may contact my research supervisor in writing or via telephone:

Dr Helen Combes  
Staffordshire University  
Clinical Psychology Professional Doctorate  
Faculty of Health Sciences - Science Centre  
Staffordshire University  
Leek Road  
Stoke-on-Trent  
ST4 2DF  
Contact Telephone number- t: 01782 294007 f: 01782 295785  
Contact E-mail: [H.A.Combes@staffs.ac.uk](mailto:H.A.Combes@staffs.ac.uk)

#### **What if I feel upset or distressed after my participation in the study?**



The researcher is keen to ensure the good psychological well-being of all participants. As mentioned at the end of the study, you are able to access specialist psychological support on any of the below contacts:

1) Dr Marilyn Owens  
Macmillan Consultant Clinical Psychologist  
Severn Hospice  
Apley Castle  
Telford  
TF1 6RH  
Tel: 01952 221350  
Fax: 01952 221360

Dr Marilyn Owens will support you to access specialist psychological support in cancer and palliative care at Severn hospice. Please feel free to contact her via writing or telephone.

2) The Hamar Help and Support Centre  
Royal Shrewsbury Hospital  
Mytton Oak Road  
Shrewsbury  
SY3 8XQ  
Tel: 01743261035

Fax: 01743261465

Email: [hamarcentre@sath.nhs.uk](mailto:hamarcentre@sath.nhs.uk)

Please feel free to telephone or 'drop-in' to the Hamar Centre for general information, or to book an appointment for psychological support. They are open 9.00am to 5.00pm Monday to Friday.

You can also contact your General Practitioner (GP), who will be able to refer you onto the appropriate services.

If you have any questions about the study please feel free to contact me on the below address or email stating your name and how you would like me to contact you.

Fiona Broderick (Trainee Clinical Psychologist)

Contact Address: Clinical Psychology Professional Doctorate  
Faculty of Health Sciences - Science Centre  
Staffordshire University  
ST4 2DF

Contact E-mail: [b027439b@student.staffs.ac.uk](mailto:b027439b@student.staffs.ac.uk)

**Thank you for taking part in this study!**

## Appendix D2- Debrief for those who completed the study.

### Staffordshire & Keele Universities Doctorate in Clinical Psychology

#### DClinPsy

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Leek Road, Stoke-on-Trent ST4 2DF

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T +44 (0)1782 - 294007

W <http://www.staffs.ac.uk>



Keele University

#### Thank you for taking part in the following study titled:

#### **Living with secondary cancer: the role of post-traumatic stress (PTS) and post traumatic growth (PTG).**

Your input and effort has been much appreciated! The data you have provided will be anonymised and stored in a locked filing cabinet, and your audio recording will be immediately transcribed and deleted from the recording device. All data will be analysed once data has been collected from each participant, and this will take place on a safe booted and password protected NHS laptop. Once the data has been analysed it will be written up within a research project.

As discussed, this research aims to provide insight into the viewpoints of people with secondary cancer and their partners, through examining the meanings they give to this experience. Findings from the study should increase our understanding of the healthcare needs of people with secondary cancer, and improve psychological treatment of these individuals and those that care for them.

I would like to emphasise that if you are unhappy about any aspect of the way you have been approached or treated during the course of the study, you may contact my supervisor:

Dr Helen Combes  
Clinical Lecturer and Chartered Clinical Psychologist  
Staffordshire University  
Clinical Psychology Professional Doctorate

Faculty of Health Sciences - Science Centre  
Staffordshire University  
Leek Road  
Stoke-on-Trent  
ST4 2DF  
Contact Telephone number- t: 01782 294007 f: 01782 295785  
Contact E-mail: H.A.Combes@staffs.ac.uk

### **What if I feel upset or distressed after my participation in the study?**

The researcher is keen to ensure the good psychological well-being of all participants. As mentioned at the end of the study, you are able to access specialist psychological support on any of the below contacts:

1) Dr Marilyn Owens  
Macmillan Consultant Clinical Psychologist  
Severn Hospice  
Apley Castle  
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TF1 6RH  
Tel: 01952 221350  
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Dr Marilyn Owens will support you to access specialist psychological support in cancer and palliative care at Severn hospice. Please feel free to contact her via writing or telephone.

2) The Hamar Help and Support Centre  
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SY3 8XQ  
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Email: [hamarcentre@sath.nhs.uk](mailto:hamarcentre@sath.nhs.uk)

Please feel free to telephone or 'drop-in' to the Hamar Centre for general information, or to book an appointment for psychological support. They are open 9.00am to 5.00pm Monday to Friday.

You can also contact your General Practitioner (GP), who will be able to refer you onto the appropriate services.

### **How do I withdraw my data?**

As emphasised throughout this process, you can withdraw your data at any stage up until the research has been submitted for publication. To do this, please contact the researcher either in writing (via email or letter), and state your name and that you wish to withdraw your data. If you would like to speak to the researcher about this, please request this within your email/letter and advise how you would like to be contacted. You do not have

to give any reason for wishing to withdraw. Upon withdrawal, all information related to your participation in the study will be destroyed. Further, a decision to withdraw at any time, or a decision not to take part, will not have any effect on your (or your partner's) treatment or care.

Fiona Broderick (Trainee Clinical Psychologist)

Contact Address: Clinical Psychology Professional Doctorate  
Faculty of Health Sciences - Science Centre  
Staffordshire University  
ST4 2DF

Contact E-mail: [b027439b@student.staffs.ac.uk](mailto:b027439b@student.staffs.ac.uk)

If you have any questions about the study please feel free to contact me on the above address or email stating your name and how you would like me to contact you.

**Thank you for taking part in this study!**

## **Appendix E: Q-Statement codes**

Examination of the theories and literature on post-traumatic stress and post-traumatic growth yielded a total of thirteen codes: Personal Growth, 'Meaningful Relationships', 'Richer Existential and Spiritual Life', 'Increased Appreciation for Life', 'Changed Priorities', , 'Negative beliefs about self/world/others', 'Negative interpretations of consequences of cancer', 'Intrusions', 'Arousal', 'Negative Emotion', 'Disrupted Memory', 'Dissociation' and 'Avoidance'.

A further four codes were added as they were prominent within the PTS/PTG literature in relation to cancer: 'Illusory Growth', 'Awareness of the Body', 'Cognitive Processing' and 'Stressors'.

## Appendix F: Q-Set Statements

Q-Statements	
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.
2	I've learned to do things that help me feel better (e.g., being positive, communicating, living in the present).
3	It's hard to watch the body change when cancer sets in.
4	Since finding out about the cancer, I've picked up new hobbies and learned new skills.
5	It's best to look death in the eye and to make a plan because this gives you more power!
6	I feel like I understand myself more.
7	Cancer enhances your awareness of your body and of your physical well-being.
8	Since finding out about the cancer I've taken better care of my health.
9	Trying to find a silver lining has made me feel better.
10	There's a lot of sadness behind my fake smiles and pretending.
11	I've convinced myself that something good can come from this, and that has helped.
12	I feel that I've become a better person through this (e.g., I'm more caring, stronger, more capable, wiser).
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.
14	A great day is when I've made a difference in another patient's or carer's life, by giving hope or some advice.
15	I have become more spiritual and this has allowed me to find peace.
16	With cancer you have to learn to give up the power and to manage the uncertainty it brings.
17	You need to look at what's important, and let go of the things that don't matter or that bother you.
18	I've learned a lot about how wonderful people can be.
19	Watching someone you love suffer, whether they're ill or not, fills you with sadness.
20	I've stopped myself from thinking about cancer, about what's happened since the diagnosis, and about the future
21	The possibility of death pulls you closer to people - you feel more warmth and more trust.
22	I can be completely preoccupied by the cancer, which makes it hard to concentrate on things.
23	Guilt is something I feel, for things I should have done, and for the things I can't do.
24	Certain smells, sounds, or places bring painful memories rushing back to my mind.
25	When you're going through this you just can't relate to other people and they can't relate to you.
26	I've had pictures that relate to illness and death pop into my

	mind.
27	There have been times when its felt good to ignore the cancer, to not acknowledge it.
28	Sometimes it feels like I'm reliving painful parts of the experience (e.g., diagnosis, treatment) all over again.
29	I've tried to make sense of why this has happened.
30	It feels like a rollercoaster. I've felt terrified, so incredibly scared.
31	I avoid things about cancer, things on the TV, in the news, and places I see as being connected to the experience
32	I feel as if I was chosen for this journey....it's a gift.
33	I have come to believe that if I can handle this, I can handle anything.
34	Alcohol and/or medication can help you manage how you feel.
35	Cancer has changed my view on the meaning of life.
36	Behind closed doors, I can get snappy and irritable
37	Sometimes I feel anxious, my heart beats fast, my head aches and that's when I'm thinking about the cancer.
38	I've developed valuable friendships with people in similar circumstances.
39	I feel like I'm on edge waiting for something awful to happen.
40	The treatment is the barbaric bit, having it yourself or watching its effects.
41	I've had upsetting nightmares which have left me feeling drained.
42	Parts of this experience have been horrendous and I feel like the memories of it are very powerful.
43	I'm nervous to let out all the emotions I'm hiding, because If I opened up I'd fall apart.
44	Stories of how others have coped with cancer have changed how I view the illness.
45	People with cancer can feel disgusting, disfigured, or defected.
46	When I found out about the cancer the future ground to a halt. Things seem pointless now.
47	I've felt numb, almost as if I was dead inside.
48	Since finding out about the cancer, parts of my memory feel hazy, as if bits of it are missing.
49	The world has come to feel more dangerous and scary.
50	I look at how I've coped with all this and I think I'm a weak person.
51	Cancer teaches you that your own body can turn on you and let you down.
52	Cancer has made me rethink how I want to live my life. I've changed my priorities.
53	I think the hardest part is always waiting to hear the results of tests.
54	The worst bit was finding out that the cancer was incurable.
55	I get tremendous pleasure from creating new memories. It motivates me and keeps me going
56	Having earlier traumatic life experiences affects the way you

	cope with cancer.
<b>57</b>	Cancer causes you to appreciate the small things in life; you stop and smell the roses.
<b>58</b>	I feel like I've become more open to opportunities.
<b>59</b>	I have anger building up inside of me. I'm angry because I can't change anything.
<b>60</b>	I've felt like no one cares, like no one notices me.
<b>61</b>	There have been times when I've felt spaced out and missed things people have said.
<b>62</b>	There have been times when I've thought that cancer wasn't real, as if it wasn't happening.



## Appendix G: Demographics Questionnaires

### Appendix G1- Demographics questionnaire for patients

## Staffordshire & Keele Universities

## Doctorate in Clinical Psychology

### DClinPsy

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E [DClinPsy@staffs.ac.uk](mailto:DClinPsy@staffs.ac.uk)

T +44 (0)1782 - 294007

W <http://www.staffs.ac.uk>



How would you describe your gender? .....

Please tick to indicate what age range you are within?

18-30

31-40

41-50

51-60

61-70

71-80

81-90

91+

How would you describe your ethnicity?.....

What type of cancer do you have?.....

What date (approximately) did you receive your diagnosis/diagnoses?.....

Have you received talking therapy to discuss the impact of cancer?.....

THANK YOU FOR TAKING TIME TO COMPLETE THIS FORM- IT IS VERY MUCH APPRECIATED!

## Appendix G2- Demographics questionnaire for partners.

### Staffordshire & Keele Universities

### Doctorate in Clinical Psychology

#### DClinPsy

Faculty of Health Sciences, Staffordshire University,  
Leek Road, Stoke-on-Trent ST4 2DF  
E [DClinPsy@staffs.ac.uk](mailto:DClinPsy@staffs.ac.uk)  
T +44 (0)1782 - 294007  
W <http://www.staffs.ac.uk>



Keele University

How would you describe your gender? .....

Please tick to indicate what age range you are within?

18-30

31-40

41-50

51-60

61-70

71-80

81-90

91+

How would you describe your ethnicity?.....

What type of cancer does your partner have?.....

Have you ever been diagnosed with cancer?.....

What date (approximately) did your partner receive their  
diagnosis/diagnoses?.....

Have you had any talking therapy to explore the impact of caring for someone with  
cancer?.....

THANK YOU FOR TAKING TIME TO COMPLETE THIS FORM- IT IS VERY MUCH  
APPRECIATED!

## Appendix H: Pair-wise Correlation Coefficients' for Q-sorts

Table H: Pair-wise Correlation Coefficients' for Q-Sorts

Q-sort	01	02	03	04	05	06	07	08	09	10	11
01	1.00	<u>0.50</u>	0.49	-0.05	0.17	0.39	0.14	0.39	0.35	0.43	0.52
02		1.00	0.50	0.20	0.16	0.22	0.24	0.15	0.22	0.25	0.26
03			1.00	0.16	0.10	0.15	0.21	0.21	0.23	0.19	0.47
04				1.00	-0.03	0.17	0.33	-0.01	0.00	-0.13	<u>0.16</u>
05					1.00	0.25	0.34	-0.13	-0.10	0.16	0.18
06						1.00	0.30	0.25	0.39	0.36	0.44
07							1.00	0.11	0.03	0.07	0.49
08								1.00	0.48	0.53	0.32
09									1.00	0.41	0.33
10										1.00	0.37
11											1.00

**Note** Significant correlations are emboldened ( $r \geq 0.33$ ,  $p < 0.01$ , Brown, 1980).  
Correlations between the patients and their respective partners are underlined.

## Appendix I: Factor Arrays and Distinguishing Statements for each Factor

### Factor array for factor one.

-6	-5	-4	-3	-2	-1	0	1	2	3	4	5	6
25	32	20	22	6	3	1	7	5	9	11	2	21
34	50	24	26	15	4	8	14	17	12	13	18	54
	60	31	29	27	23	10	35	37	19	16	52	
		62	45	41	28	30	38	42	43	57		
			49	47	36	33	44	56	55			
				48	40	46	51	61				
					58	53	59					
						39						

### Factor array for factor two.

-6	-5	-4	-3	-2	-1	0	1	2	3	4	5	6
39	22	28	31	3	9	4	6	8	1	12	33	2
46	50	29	23	10	21	5	11	16	7	15	34	35
	60	43	24	13	25	27	19	18	14	17	57	
		54	59	26	45	36	20	38	52	44		
			41	30	47	40	32	56	55			
				37	49	42	48	62				
					51	53	58					
						61						

### Factor array for factor three.

-6	-5	-4	-3	-2	-1	0	1	2	3	4	5	6
32	4	41	24	26	22	6	9	2	5	17	1	10
44	11	55	28	29	30	7	12	16	18	36	3	19
	13	58	31	33	34	8	15	21	20	39	53	
		49	45	37	35	14	23	27	42	40		
			50	38	46	52	25	51	43			
				59	47	54	48	57				
					61	60	56					
						62						

**Factor array for viewpoint four.**

-6	-5	-4	-3	-2	-1	0	1	2	3	4	5	6
32	43	29	38	6	5	33	26	2	8	3	15	18
25	60	44	48	59	27	19	1	13	30	31	37	40
	23	35	61	36	22	20	9	10	45	51	34	
		56	41	4	12	46	17	39	47	54		
			49	58	11	14	16	53	62			
				48	50	7	55	42				
					21	24	57					
						28						

**Table I1: Distinguishing statements for factor one.**

no	Statements-abbreviated	Rating	Z Score
21	The possibility of death pulls you closer to people	6	2.07*
54	Worst bit was finding the cancer was incurable	5	1.51*
13	I've been in the middle of something and it hits me	4	1.12*
37	I feel anxious when I'm thinking about the cancer	2	0.74*
59	I'm angry because I can't change anything	1	0.38
44	Stories of coping has changed view on the illness	1	0.38
33	If I can handle this, I can handle anything	0	0.20
1	It doesn't matter how long on this planet	0	0.19
39	I'm on edge waiting for something awful to happen	-1	-0.37*
20	I've stopped myself from thinking about cancer	-4	-0.32*
62	I've thought that cancer wasn't real	-5	-1.69
25	You can't relate to other people	-6	-1.88*
34	Alcohol, medication helps you manage feelings	-6	-2.07*

**Table I2: Distinguishing statements for factor two.**

no	Statements-abbreviated	Rating	Z Score
35	Cancer has changed my view on the meaning of	6	2.06*
33	If I can handle this, I can handle anything	5	1.40*

34	Alcohol, medication helps you manage feelings	5	1.34*
44	Stories of coping has changed my view on illness	4	1.29
15	I have become more spiritual and found peace	4	1.19
62	I've thought that cancer wasn't real	2	0.81*
32	I feel as if I was chosen for this journey	1	0.53*
5	It's best to look death in the eye and to make a plan	0	-0.14
42	This experience was horrendous, memories are powerful	0	-0.15
13	I've been in the middle of something and it hits me	-2	-0.55
43	I'm nervous to let out all the emotions I'm hiding	-4	-1.16*
54	Worst bit was finding the cancer was incurable	-4	-1.42*
39	I'm on edge waiting for something awful to happen	-6	-2.02
46	Future ground to a halt. Things seem pointless now	-6	-2.11

**Table I3: Distinguishing statements for factor three.**

no	Statements-abbreviated	Rating	Z Score
10	There's a lot of sadness behind my fake smiles	6	1.86*
53	Hardest part is waiting to hear test results	5	1.57*
3	It's hard to watch the body change	5	1.57*
40	The treatment is the barbaric bit	4	1.37*
36	Behind closed doors, I get snappy and irritable	4	1.28*
39	I'm on edge waiting for something awful to	4	1.16*
2	I've learned to do things that help me feel better	2	0.58
54	Worst bit was finding the cancer was incurable	0	0.20*
60	No one cares, like no one notices me	0	0.08*
52	Cancer has made me rethink how I want to live	0	0.04
34	Alcohol, medication helps you manage feelings	-1	-0.16*
62	I've thought that cancer wasn't real	-1	-0.49
38	I've developed friendships with people in sim situ	-2	-0.58
33	If I can handle this, I can handle anything	-2	-0.91
55	I get pleasure from creating new memories	-4	-1.07*
58	I've become more open to opportunities	-4	-1.49*
13	I've been in the middle of something and it hits	-5	-1.57
11	I've convinced myself that good can come from	-5	-1.69*
4	I've picked up new hobbies and skills	-5	-1.74*
44	Stories of coping has changed my view on illness	-6	-1.78*

## Appendix J: Statement Rankings

**Table J1: Statement rankings across factors one, two, three, and viewpoint 4.**

Q-Statements		1	2	3	4
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.	0	3	5	1
2	I've learned to do things that help me feel better (e.g., being positive, communicating, living in the present).	5	6	2	2
3	It's hard to watch the body change when cancer sets in.	-1	-2	5	4
4	Since finding out about the cancer, I've picked up new hobbies and learned new skills.	-1	0	-5	-2
5	It's best to look death in the eye and to make a plan because this gives you more power!	2	0	3	-1
6	I feel like I understand myself more.	-2	1	0	-2
7	Cancer enhances your awareness of your body and of your physical well-being.	1	3	0	0
8	Since finding out about the cancer I've taken better care of my health.	0	2	0	3
9	Trying to find a silver lining has made me feel better.	3	-1	1	1
10	There's a lot of sadness behind my fake smiles and pretending.	0	-2	6	2
11	I've convinced myself that something good can come from this, and that has helped.	4	1	-5	-1
12	I feel that I've become a better person through this (e.g., I'm more caring, stronger, more capable, wiser).	3	4	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.	4	-2	-5	2
14	A great day is when I've made a difference in another patient's or carer's life, by giving hope or some advice.	1	3	0	0
15	I have become more spiritual and this has allowed me to find peace.	-2	4	1	5
16	With cancer you have to learn to give up the power and to manage the uncertainty it brings.	4	2	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.	2	4	4	1
18	I've learned a lot about how wonderful people can be.	5	2	3	6
19	Watching someone you love suffer, whether they're ill or not, fills you with sadness.	3	1	6	0
20	I've stopped myself from thinking about cancer, about what's happened since the diagnosis, and about the future	-4	1	3	0
21	The possibility of death pulls you closer to people - you feel more warmth and more trust.	6	-1	2	-1

22	I can be completely preoccupied by the cancer, which makes it hard to concentrate on things.	-3	-5	-1	-1
23	Guilt is something I feel, for things I should have done, and for the things I can't do.	-1	-3	1	-5
24	Certain smells, sounds, or places bring painful memories rushing back to my mind.	-4	-3	-3	0
25	When you're going through this you just can't relate to other people and they can't relate to you.	-6	-1	1	-6
26	I've had pictures that relate to illness and death pop into my mind.	-3	-2	-2	1
27	There have been times when its felt good to ignore the cancer, to not acknowledge it.	-2	0	2	-1
28	Sometimes it feels like I'm reliving painful parts of the experience (e.g., diagnosis, treatment) all over again.	-1	-4	-3	0
29	I've tried to make sense of why this has happened.	-3	-4	-2	-4
30	It feels like a rollercoaster. I've felt terrified, so incredibly scared.	0	-2	-1	3
31	I avoid things about cancer, things on the TV, in the news, and places I see as being connected to the experience	-4	-3	-3	4
32	I feel as if I was chosen for this journey....it's a gift.	-5	1	-6	-6
33	I have come to believe that if I can handle this, I can handle anything.	0	5	-2	0
34	Alcohol and/or medication can help you manage how you feel.	-6	5	-1	5
35	Cancer has changed my view on the meaning of life.	1	6	-1	-4
36	Behind closed doors, I can get snappy and irritable	-1	0	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.	1	2	-2	-3
39	I feel like I'm on edge waiting for something awful to happen.	0	-6	4	2
40	The treatment is the barbaric bit, having it yourself or watching its effects.	-1	0	4	6
41	I've had upsetting nightmares which have left me feeling drained.	-2	-3	-4	-3
42	Parts of this experience have been horrendous and I feel like the memories of it are very powerful.	2	0	3	2
43	I'm nervous to let out all the emotions I'm hiding, because If I opened up I'd fall apart.	3	-4	3	-5



44	Stories of how others have coped with cancer have changed how I view the illness.	1	4	-6	-4
45	People with cancer can feel disgusting, disfigured, or defected.	-3	-1	-3	3
46	When I found out about the cancer the future ground to a halt. Things seem pointless now.	0	-6	-1	0
47	I've felt numb, almost as if I was dead inside.	-2	-1	-1	3
48	Since finding out about the cancer, parts of my memory feel hazy, as if bits of it are missing.	-2	1	1	-3
49	The world has come to feel more dangerous and scary.	-3	-1	-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.	5	3	0	-2
53	I think the hardest part is always waiting to hear the results of tests.	0	0	5	2
54	The worst bit was finding out that the cancer was incurable.	6	-4	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.	4	5	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.	1	-3	-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.	2	0	-1	-3
62	There have been times when I've thought that cancer wasn't real, as if it wasn't happening.	-4	2	0	3

## Appendix K: Consensus Statements

**Table K1: Consensus statements.**

Statements-abbreviated		F1	F2	F3
2	I've learned to do things that help me feel better	5	6	2
6	I feel like I understand myself more	-2	1	0
7	Cancer enhances your awareness of your body	1	3	0

8	Since finding out I've taken care of my health	0	2	0
12	I feel that I've become a better person	3	4	1
14	A great day is when I've made a difference	1	3	0
16	You have to give up power and manage uncertainty	4	2	2
17	Look at what's important, and let go of things	2	4	4
18	I've learned about how wonderful people can be	5	2	3
24	Certain smells, sounds, places bring memories	-4	-3	-3
26	Pictures of illness and death pop into my mind	-3	-2	-2
27	It's felt good to ignore the cancer	-2	0	2
28	It feels like I'm reliving parts of the experience	-1	-4	-2
29	Tried to make sense of why this has happened	-3	-4	-2
30	It feels like a rollercoaster	0	-2	-1
31	I avoid things about cancer	-4	-3	-3
41	I've had upsetting nightmares	-2	-3	-4
45	People with cancer can feel disgusting	-3	-1	-3
47	I've felt numb, almost as if I was dead inside	-2	-1	-1
48	Parts of my memory feel hazy	-2	1	1
50	I look at how I've coped and I think I'm a weak	-5	-5	-3
51	Your own body can turn on you	1	-1	-2

# **Reflective Account: Personal Learning, Challenges, and Changes**

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## **Introduction**

This paper offers a reflective summary of my journey to creating the thesis: 'Exploring the Traumatic Impact of Advanced Cancer'. Primarily, I have outlined the study's rationale and have provided an overview of my learning at key stages in the research process. To conclude, I have

presented themes from my reflective journal, which describe the personal challenges and changes I have encountered on my research journey.

### **Selecting a Research Topic**

In considering which clients activate a sense of curiosity in my practice, it is those that are living with a physical health problem. While these clients can be “devastated” and “broken” in being diagnosed with a life-threatening illness, they also report positive changes, such as gaining a new appreciation of life. In exploring the evidence base for a theoretical framework to understand these seemingly contradictory responses to illness, I discovered the trauma literature. This literature frames illness as a threatening and traumatic event which has the potential to elicit both positive and negative responses within an individual (Brennan, 2001, Jim & Jacobsen, 2008). I chose to focus on advanced cancer (AC), as discussions with health care professionals and material within the media (Channel 4, 2014, Novartis Oncology, 2013) indicated that living with incurable cancer can be traumatic. Further, the majority of literature on ‘cancer and trauma’ had been conducted with individuals in remission, or in the earlier-stages of the illness (Hefferon et al., 2009, Kangas et al., 2002, Smith et al., 1999). Therefore, focusing on trauma in individuals living with AC was a novel and necessary research topic.

### **Why Q-methodology?**

I was enthused to discover Q-methodology and I believe it to be a very valuable research technique. I perceive its strength to be in its amalgamation of quantitative and qualitative data, which permits both a post-positivist and constructionist approach to examining phenomena (Ramlo & Newman, 2011). Through the self-referential Q-sorting process, this technique allowed me to explore the realities of my participants. I was then able to interpret these realities in an objective manner, using quantitative data analysis.

## **Learning through the Research Process**

### **Cancer Care: Entering into the Unknown**

In commencing my literature review, my realisation of the amount of research on cancer, and my absent clinical experience in palliative care, generated apprehension. I explored cancer websites, had discussions about my research project with palliative care professionals, and spent time with patients at the hospice. I also examined the broader evidence base on the psychological impact of cancer (Appendix A). These efforts enhanced my understanding of the subject and experience of palliative illness, and eased my anxiety about conducting research in a setting that was novel to me. Richardson (2014) suggested research can be used as a form of “graded exposure” (p.11), to reduce one’s fear and avoidance of being a scientist-practitioner. Indeed, this research experience has been a valuable “graded exposure” task. I initially felt anxious and was concerned about my ability to effectively implement and report on my research. However, over time, I gained confidence in being a scientist-practitioner, my anxiety reduced, and I learned that I can competently conduct research to contribute to the evolving evidence base.

### **Planning the Study**

The planning stage of my research was dominated by a sense of excitement. This blinded me from considering potential obstacles in implementing the research in real life. My enthusiasm meant that I spent an excessive amount of time planning my study, and had generated very detailed protocols. However, at times this meant that I could not be flexible in how I gathered my data. For example, I planned for participants to complete the Q sort in an independent manner, without conversation occurring between myself and the participant. Their reflections on the Q-sort were then to be recorded in a ‘post-sort interview’. However, in practice, some participants wished to discuss their experiences as they completed the Q-sort. It may have been helpful to voice record this reflection, but my protocol did not allow for this.

This experience has taught me to consider the following questions when planning future research:

- In implementing this research in real life, what challenges am I likely to encounter?
- Is there enough flexibility in the protocol to ensure that data can be collected in a responsive manner, in line with the individual's personal style?
- Can I involve service users at the planning stage to gain feedback on how they might interact with the research process?

### **Ethical Considerations**

Throughout this project, I was keen to ensure that the rights, dignity and wellbeing of participants were be considered in detail (Department of Health, 2005). Many of my participants were physically unwell, and I attempted to be sensitive to this, by offering breaks. I was also aware that I was asking participants to reflect on an emotionally challenging experience, which may cause them distress. I therefore employed certain safeguards. Consistent with professional guidelines (British Psychological Society 2009, British Psychological Society, 2010, Department of Health, 2005), I sought to consider the research from the standpoint of the participants throughout the research process. To screen out participants who may have found the study too distressing, when gaining consent, I ensured that they understood the purpose of the study, their role, and the consequences of taking part. I also debriefed each participant, in which I explained their right to withdraw their data, and asked about their feelings in response to the research task. Consistent with professional guidelines (British Psychological Society 2009, British Psychological Society, 2010), each participant's data was recorded, processed, and stored in a manner that ensured confidentiality and anonymity. These various safeguarding procedures ensured that the study was ethically sound, and responsive to the setting in which I was collecting data.

## **Making the study accessible and inclusive**

From the outset, I wished to make the research inclusive. For example, I designed the inclusion criteria to ensure that individuals' with AC were able to participate, independent of having a partner opting-in to the study. Similarly, I also specified that partners were able to participate, without the person they were caring for opting to participate.

I also aimed to ensure that the study was accessible. One participant, who was keen to be involved in the study, was visually impaired. This person's participation extended over two sessions, and involved adaptations to the Q-set. Statements were printed in very large, bold font. This participant was very grateful of being involved in the study, as she found it useful in helping her identify the positive ways in which she had managed her AC.

## **Materials**

### **Creating the Q-set.**

Within Q-methodology, the researcher creates the data gathering tool, termed the Q-set (Watts & Stenner, 2012). This stage was the most time consuming component of the research journey (Appendix B). As I am a novel Q-methodologist I was plagued by concerns around whether my process was correct and rigorous. I managed this anxiety through attending a two day workshop on Q-methodology, engaging in supervision, and gaining guidance from others within the Q-community. Through this, I learned how beneficial it is to integrate into a research community. Networking with other Q-methodologists developed my confidence in my understanding of the approach and the research decisions I had made.

### **Recruitment.**

Recruitment proved to be the most challenging aspect of my research. Approximately 200 participant information packs were provided to professionals at the recruiting hospices. After four months of recruiting, I had gathered data from only four participants. I was relying on other professionals to access participants on my behalf, which limited my control over the recruitment process. This experience was, at times, unnerving. I

promoted the study through attending a team meeting, and spent time on the hospice day units to liaise with staff and identify participants. I also asked a participant to provide feedback with regards to the study information pack, to determine if this posed any barriers to engagement. However, she confirmed that she had found it “interesting”, and did not feel that it would deter any potential participants. After six months of persistent efforts, and a great deal of support from professionals working at the hospice, I had obtained data from 11 participants.

In hindsight, it may have been beneficial to recruit participants from the community, as opposed to those engaging in hospice care. This may have provided a more varied and larger sample. Within this process, I learned of how the psychologists’ skills of communication, building rapport, and working in partnership (British Psychological Society, 2008) were vital to successful recruitment. My insight into the limited control a researcher can encounter during recruitment has also been beneficial. I can better tolerate this in the future research, and once qualified will always take time to support other researchers in their recruitment efforts.

## **Data Analysis**

The data analysis (Appendix C) was the most enjoyable component of the research, as I learned of the mass of rich data acquired through Q-methodology. I spent time examining my quantitative data, and being immersed in the accompanying qualitative material. I learned that the Psychologist’s skills of formulation and hypothesis testing (Health and Care Professions Council, 2012) are fundamental to Q-factor interpretation, as I had to develop and test hypotheses about the stories contained within each factor (Watts & Stenner, 2012). This process of interpretation can introduce bias (Rogers, 1991). I thus adopted a range of strategies to prevent my own personal experiences and research expectations from impacting on the conclusions I had drawn:

- I completed my own Q-sort prior to gathering data, in order to enhance my awareness of my personal viewpoint (Appendix D).



- As I am living with a degenerative eye disease, I identified which aspects of the constructs being exploring (PTS and PTG) resonated with my own experience of illness (Appendix E).
- I asked my supervisors to examine my analyses and verify conclusions that I had drawn from the data.
- I completed a short reflection subsequent to each interview, to guide my understanding of each participant's experience (Appendix F).

### **Considering my Own Responses**

In developing as a self-aware and safe practitioner, I have found it valuable to have a working formulation of how my beliefs can influence my practice as a psychologist. Therefore, in order to develop as an ethical and effective researcher, it seems apt to revisit this formulation, and to consider how my beliefs have impacted on my functioning as a researcher (Appendix G). This formulation will enhance my self-awareness for conducting research in the future. Examination of the content of my reflective diary revealed three triggers within the research process, which generated an emotive responses: 'The Research Process', 'Participants in Distress' and the topic of 'Death and Loss'. Accordingly, I have considered how these triggers activated my negative beliefs, and could have caused me to respond in an unhelpful manner. In the below description, comments from my reflective diary are italicised.

### **Uncertainty within the Research Process**

Various stages of my research journey were punctuated by periods of self-criticism and self-doubt. This self-doubt was triggered by any sense of uncertainty within the research process. For example, when I had limited control over the outcome of recruitment, and when I was uncertain my research decisions, I became increasingly self-critical:

*I am concerned that X is wrong; I need to understand X more; I have struggled to commit to a review topic; May be I could be doing something different to boost recruitment.*

This self-criticism and self-doubt relate to my belief of “not being good enough”. These thought processes precipitated anxiety, which dampened my excitement about the research. My diary indicates that I managed my negative thoughts and feelings by ruminating on small decisions, and reading an excessive amount. These behaviours meant that numerous research tasks took more time than necessary.

In recognising that my negative belief of “not being good enough” was influencing my response to the research process, I made active efforts to manage this. I acknowledged that my ‘self-doubt’ was present and most likely tainting my perception of my research. I curbed my rumination and allocated clear deadlines for research activities. I also reminded myself that each research decision I had made was carefully considered, and was therefore justifiable and likely to be sound.

### **Participants in Distress**

At times, conducting research with individuals who were physically unwell and distressed, triggered potentially unhelpful thought processes and excessive worry regarding their emotional well-being:

*I felt concerned about pushing her; What if I caused her to become upset; I was concerned she'd feel sad and would be on her own after the interview.*

These thought processes relate to my belief that ‘other people are fragile’, and my tendency to ‘protect others’. Within my first interview, these thoughts generated a sense of apprehension and were at risk of effecting my behaviour. Reflections indicated that, at times, I felt reluctant to explore distressing material (“*I felt the need to pull back*”). I also commented on the difficulty of acting as a ‘researcher’ as opposed to a therapist, in response to the participants becoming distressed (“*I had to stop myself from being drawn into the therapist's role*”). Examination of the transcript from this interview

indicated that my personal concerns had not influenced the participant's responses. However, I realised that persistently being worried about participants becoming upset could negatively impact on their experience, and the quality of the data; participants' desires to share distressing material in a safe space may be denied, and the data may not be a true reflection of their experience and feelings.

To ensure that my concerns did not have an unhelpful impact on my behaviour, I closely monitored the way in which I responded to participants, ensuring that I was exploring distressing material in an appropriate and containing manner. I was also vigilant for signs that I was being drawn into relating to participants as a therapist (as opposed to a researcher). Through this experience, I learned that I can engage in safe and appropriate exploration of distressing material, and can be empathic and responsive to a participant's sadness, while being a researcher.

### **Death and Loss**

Similarly to psychotherapists working with trauma (Arnold et al., 2005), my reflective diary demonstrated that studying incurable illness triggered both a positive and negative response within me. From a negative stance, my participants' stories activated my beliefs about the 'world being unfair', as shown by my thought processes:

*I was struck by how unlucky she had been; I felt a sense of unfairness in hearing of his struggle.*

These thoughts precipitated some sadness, which was compounded by the countertransference. I was mindful to ensure that this emotion did not impact on my interaction with participants. This sadness was also accompanied by a sense of enlightenment. I felt moved in listening to the participants' stories. I was impressed by their resilience, and experienced a strengthened appreciation of my own life, and of my family.

*I wondered how she was able to get through each day, even with feeling so drained and scared; In listening to how her partner had*

*supported her. I was reminded of how supportive my own partner had been.*

Through meeting these participants, I have learned how people can be brave, despite feeling devastated by their illness. Their stories reminded me of the need to capture and appreciate happy moments in life, and to expect and be 'ok' with the uncertainty that is inherent in being alive. I have always possessed a mild fear of illness, and believed that I would not cope well in facing my own impending death. However, I have been reassured and inspired by my participants. Most importantly, I have come to realise that death and loss is an experience endured by all individuals at some stage in their life. Through witnessing the diverse ways in which participants coped with the knowledge of impending death, I have learned that while I do not have control over how I die, I have some choice in how I respond to it.

### **Learning from my participants**

*I was shocked at how she did not show any fear or anger in no longer being able to see. I felt reassured and inspired.*

One participant's story highlighted the profound impact that participants can have on the researcher. This is particularly true in circumstances where an aspect of the participant's experience resonates with our own. As mentioned, one individual participating in the study was visually impaired as a result of her brain metastases. Many of her reflections related to her loss of vision. She had a positive and patient attitude toward adapting to life without sight (*It's a case of readapting whatever happens to your body*). This experience has inspired me to manage changes in my own vision in the future with strength, adaptability, and positivity.

### **Conclusion**

This account has summarised my personal reflections, and the challenges I have encountered, during the course of my research journey. These challenges have been beneficial, as they have allowed me to learn, and to develop as a scientist practitioner (Shapiro, 2002). Through my

formulation, I have enhanced my self-awareness in functioning as a researcher. This will be valuable in conducting future research. I have a better understanding of the detrimental impact of my self-doubt, and an enhanced recognition of my own response to carrying out research with participants who may be distressed. I have also gained insight into the profound effect that participants in palliative care can have on the researcher; my participants' stories enlightened me on the need to accept uncertainty and to appreciate life. They have also influenced my attitude towards my own losses.

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## Appendices

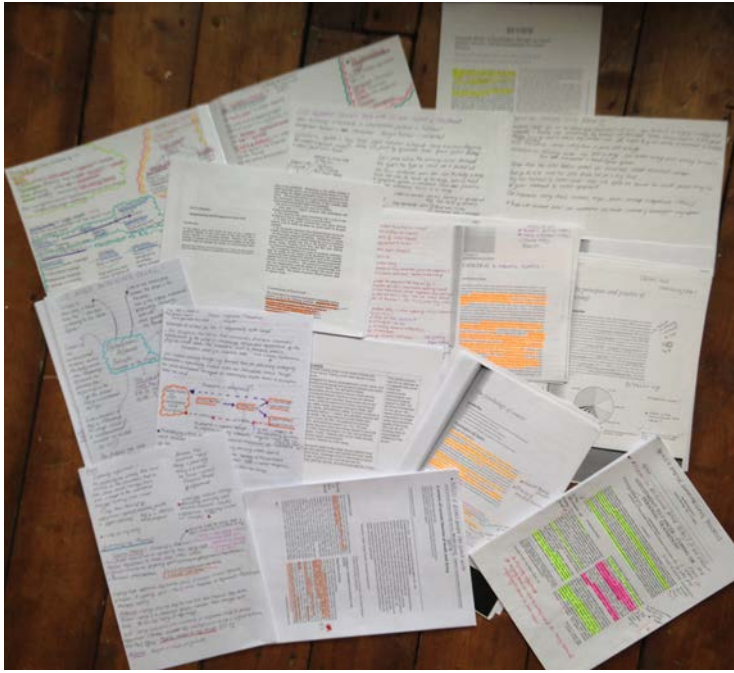
### Appendix A: Exploring the Evidence Base

These pictures depict my exploration through the psycho-oncology evidence base. Over the duration of my literature review, my limited knowledge on 'cancer care' expanded. I was able to think critically about my research question, understand the different ways in which people respond to cancer, and identify flaws in my argument. I was also able to embody the scientist-practitioner (Shapiro, 2002) using theories on grief, loss and trauma,



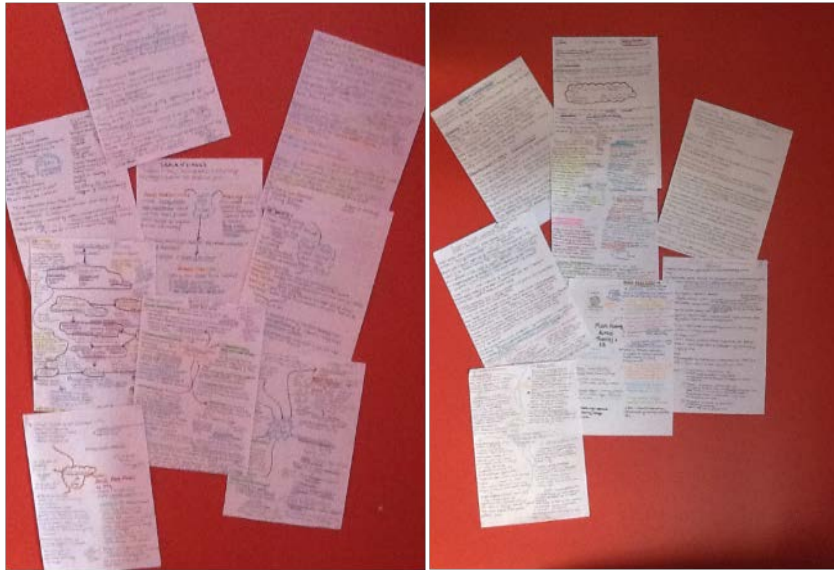
and applying them to my clinical work in an adult mental health setting.



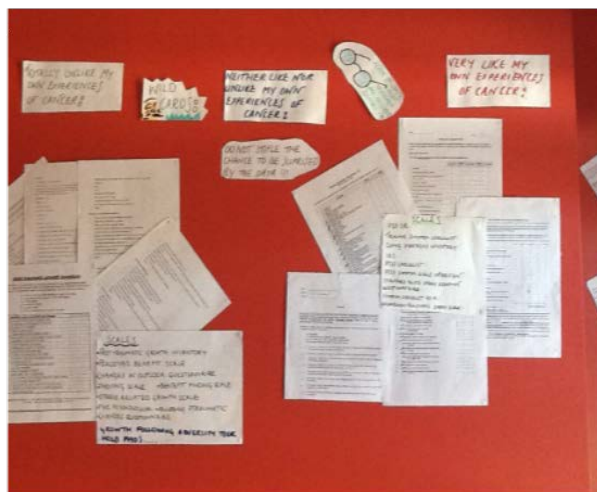


## **Appendix B: Creating the Q-Sort**

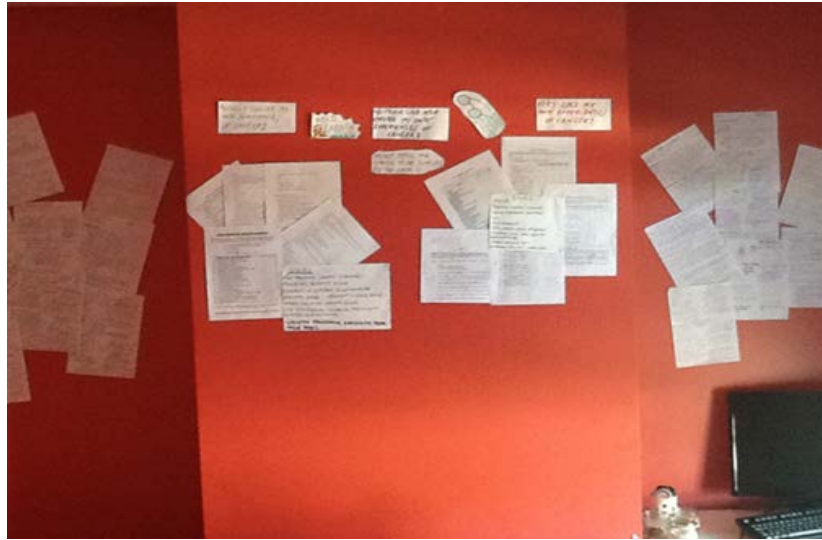
These pictures portray the development of the Q-set. Content analysis (Elo & Kyngas, 2008) was used to code and select statements which reflected the key elements of trauma theories (Picture 1). To enable this analysis, I drew out 17 key themes across theories (and scales) of PTS and PTG (Pictures 2 and 4). These themes were used to code a range of sources on the experience of AC: a four part television documentary on living with AC (Channel 4, 2014), videos featured on cancer support websites (Macmillan Cancer Support, 2014, Novartis Oncology, 2013) and a 60 minute consultation with two experienced nurses. Comments were selected if they reflected a specific theme (Pictures 5 and 6). For example, the comment “I’ve had upsetting nightmares, which have left me feeling drained” was coded within the theme ‘Intrusions’. The final set of statements were examined by a second researcher, and were assessed for readability and to ensure that they were balanced (Pictures 7 and 8). This process resulted in 62 statements that were related to the experience of AC, and that reflected key themes from trauma theories (Picture 9).



**Picture 1: Examining theories of PTS and PTG.**



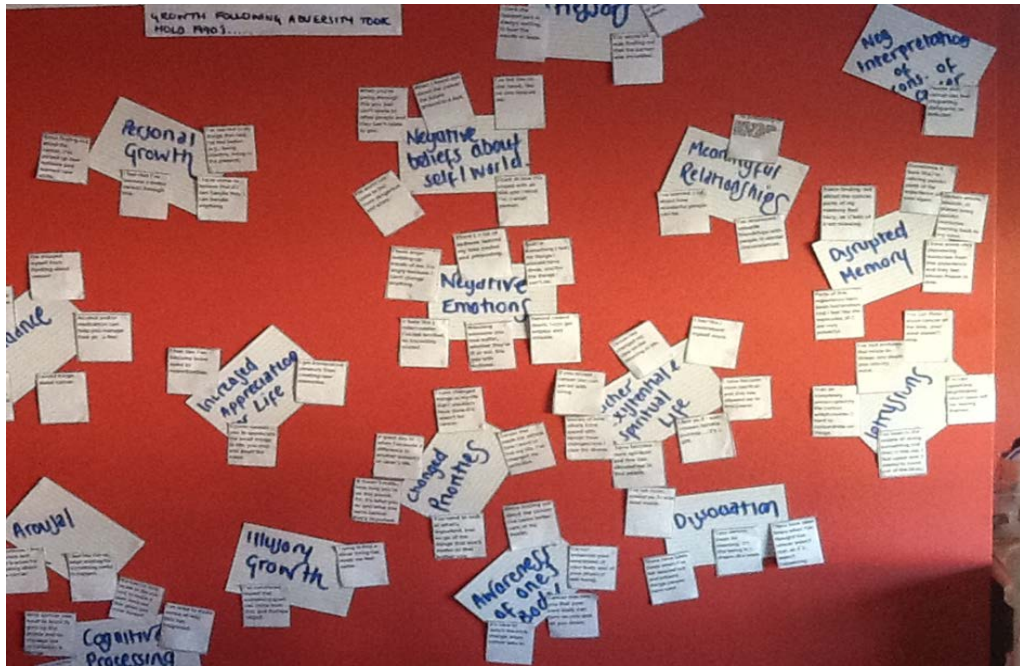
**Picture 2: Examining scales on PTS and PTG**



**Picture 3: Embarking upon content analysis**



**Picture 4: Generating codes**



Picture 5: Gathering statements which were representative of 17 key themes across theories of PTS and PTG.



Picture 6: Overview of the content analysis



I am interested in how people respond to Secondary Cancer. You have experienced secondary cancer by having the disease yourself, or by caring for someone with cancer. I would like you to rate the below statements on how much you agree with them whilst considering your own experience of living with cancer, or of providing care for someone who has cancer. Statements will be rated based on how much you agree with them, from totally agree to totally disagree.

Personal Growth	Meaningful Relationships	Higher Existential and Spiritual Life	Increased Appreciation for Life	Changed Priorities	Stressy Growth	Awareness Of the Body	Cognitive Processing
I had the 1st more means of other people's pain and suffering. I've become more caring. TD: appreciate what I can do for myself (7)	I've learned a lot about how wonderful people can be. 1	I have increased faith. I've come to believe in a higher being in a god, which has brought me peace. 2	Cancer causes you to truly appreciate even the small things in life, you sleep and eat the room. 3	A great day is when I've made a difference in another patient's or carer's life, by giving hope or some advice. 4	I've continued myself that something good can come from this, and that has helped. 5	Since finding out about the cancer I've taken better care of my health. 6	I've tried to make sense of why this has happened. 7
I have come to believe that I can handle this. I can handle anything. 8	The possibility of death puts you closer to people - you feel more warmth and more trust. 9	I feel as if I was chosen for this journey. It's a gift. 10	I've had more moments of happiness over the last few months than I've had in years. 11	I have changed things in my life that I wouldn't have done if it wasn't for cancer. 12	Trying to find a silver lining has made me feel better. 13	I listen to my body. I turn into what it's telling me and I eliminate stress from my life. 14	Stories of how others have coped with cancer has changed how I view the disease. 15
With cancer you have to learn to give up the power. To just manage the uncertainty it brings. 16	I've been overwhelmed by the support and of health care professionals. 17	Cancer's made me reassess things. I feel that I changed my belief in the meaning of life. 18	I get tremendous joy and pleasure in spending time with people, it drives me forward. 19	You need to look at what's important, (thankfully/chaotically) and let go of the things that don't matter or that bother you. 20	There's a lot of sadness behind my false smile and pretending. 21	I feel much more connected to my body. I'm more aware of it. 22	It's been to look death in the eye and to make a plan; this gives you more power. 23
I've learned to do things that help me feel better (e.g., positive thinking, communicating with others, being in the present). 24	I now know that I can rely on people. 25	If you accept cancer you can get past it. You can get on with life. Acknowledge it. 26	I feel like I've become more open as a person. I take more opportunity. 27	It doesn't matter how long you're on the planet for it's what you do, and what you leave behind that's important. 28	I need there to be a reason for why this has happened. 29	It's hard to watch my body change when cancer sets in. 30	Thinking and talking about cancer is the best thing to do. 31
I feel that I've become a better person through this (e.g., I'm stronger, more capable, more resilient, wiser). 32	I've developed friendships with people in similar circumstances. (This has been very valuable). 33	I feel like I understand myself more. 34	Cancer has changed me to develop new skills, to learn new things. 35	I feel good because I've thought how I want to live my life. I've changed my priorities. 36	Cancer teaches you that your own body can turn on you. It can let you down. 37		

Need to select 1!

Picture 7: Comments from a second researcher regarding PTG statements

Negative beliefs about with/without/when	Negative interpretations of consequences of cancer	Intimations	Anxiety	Negative Emotion	Dampened Memory And Learning	Denial/Minimisation	Avoidance	Distraction
The way I view the world has been shattered by cancer. 1	People with cancer can feel disgusting, degraded, or dejected. 2	The nightmare is something, they're intense and I had dreamt and longed about it for years. 3	There are times I feel anxious, my heart beats fast, my chest hurts, my head aches and that's when I'm thinking about the cancer. 4	Guilt is something I feel, for things I should have done, and for the things I can't do. 5	Certain smells, sounds or places bring painful memories rushing back to my mind. 6	There have been times when I've thought that cancer wasn't real, as if it wasn't happening. 7	It's felt good to ignore the cancer, to not acknowledge it. 8	I've had to witness some heart aches and sounds that will stay with me forever. 9
When I found out about the cancer my future ground to a halt, everything gets thrown out of the window and things seem pointless. 10	I look at how I've coped with all this and I think I'm a weak person. 11	The most depressing part is when you feel that you're taking care of the people who are taking care of you. 12	Behind closed doors I can get angry and irritable. 13	Watching someone you love suffer fills you with sadness. 14	I've been in the middle of doing something and then it hits me. I feel so upset and it seems to come out of the blue. 15	I've almost lost the meaning of life, it's like being in a dream-like state. 16	Alcohol and/or medication can help you manage how you feel. 17	The worst bit was finding out that the cancer was incurable. 18
The world almost felt more dangerous and more scary. 19	I think that I've taken the cancer harder because I've had so much to handle in the past. 20	You can think about cancer all the time, your mind doesn't stop. I wish someone would just switch it off. 21	I can be completely preoccupied by the cancer, which makes it hard to concentrate on things. 22	It feels like a rollercoaster. I've felt terrified, as incredibly scared. 23	I notice things about myself much more now and that can lead to me feeling very upset. 24	There have been times when I've felt spaced out and missed things people have said. 25	I'm nervous to let out all the emotions I'm holding, because if I opened up I'd feel apart. 26	The scariest bit is feeling the unknown. 27
When you're going through this you just can't relate to other people and they can't relate to you. 28	I've had pictures that relate to stress and death pop into my mind. 29	I've had pictures that relate to stress and death pop into my mind. 30	I can be very angry. I feel like I'm on edge waiting for something awful to happen. 31	I have anger bubbling up inside of me. I'm angry because I can't change anything. 32	Since finding out about the cancer, parts of my memory feel hazy, as if bits of it are missing. 33	I've purposely stopped myself from thinking about cancer, from thinking about what's happened since the diagnosis, and from thinking about the future. 34	I've purposely stopped myself from thinking about cancer, from thinking about what's happened since the diagnosis, and from thinking about the future. 35	The treatment is the hardest bit, being a patient or watching it. 36
I've felt like no one cares, like no one notices me. 37	You can know someone when you forget about cancer, but then it comes back and it smacks you in the face. 38	There have been times where I've felt sick with worry. 39	I've felt numb, almost as if I was dead inside. 40	My memories about cancer feel frozen in time and the emotion of then is still overwhelming. 41	I would think about cancer and how it has broken in time and the emotion of then is still overwhelming. 42	I would think about cancer and how it has broken in time and the emotion of then is still overwhelming. 43	Things on the TV, in the news, places I see as being connected to the experience. 44	I think the hardest part is always waiting to hear the results of tests. 45

Picture 8: Comments from a second researcher regarding PTS statements



Picture 9: The final Q-set

### **Appendix C: Determining the Factor Solution**

These pictures depict the process I used to interpret each factor. To compare across the factors, I first noted down statements that were rated at +/-6, +/-5, +/-4, using different colours to represent each ranking (Picture 1). I then observed the factor arrays (Picture 2). This allowed me to gain a general sense of each factor. After completing my initial interpretation, I explored the qualitative data provided by each participant (Picture 3). I carefully read each transcript to examine participants' reflections (and the meaning they had given) for characterising statements within each factor. I also used the transcripts to ensure that my initial interpretation of the stories told by each factor were consistent with the qualitative reflections. I then examined each factor array and the qualitative comments from participants in combination with one another (Pictures 4, 5 and 6).



Ref to Statements 8 Description of finding out cancer was incurable

326 that? And I said, well on and off for years really and I said, *when wondering*  
327 but it's got really bad recently, so I'm wondering you know if *- lining up symptoms*  
328 it's because I've been in the hospital bed or just lying down *to cancer progression*  
329 you know. So he obviously suspected immediately, so he *- waiting*  
330 sent me for a bone scan, so I had to wait a week for that *- more waiting*  
331 and I had to wait a week for the result of the bone scan, and *- way on down when*  
332 I was in the car on my own having come back from the *found out*  
333 hospital or somewhere, I can't remember where I was *- memory of hazard*  
334 coming back from, when the phone rang and he told me *- told on the phone*  
335 that the cancer had spread to my bones and therefore it *- WHAM*  
336 was classed as terminal. So it was a bit of a wham really, so *About - questioning*  
337 I was on my own and it's, you just don't know what to think *the uncertainty*  
338 really, you think well yeah, then you start to think how *how terminal?*  
339 terminal is terminal, there can't be any more terminal than *- awful*  
340 terminal can there, but how long does that mean I've got *- hopeless*  
341 and blah blah, that's when it all starts to get awful really *- cancer can't*  
342 because they just don't know. They don't know how, guess *- be cut out*  
343 it's in your bones obviously they can't operate because it's *- treatment*  
344 bits all over the place and you can't cut bones out can you, *- hope*  
345 well you can some but not others but uh, so it was then *- given a*  
346 going on to the chemo and the radiotherapy to zap it and *- deadline*  
347 hopefully got it to shrink back or whatever, which seemed, *- stabilising*  
348 touch wood, horrible table I hate this table, um, how long it *- not well enough to*  
349 was going to last. So I was told then 2-3 years, and that was *retain normal life*  
350 5 years ago, so. So for the next 2-3 years I sort of took the *- some normality*  
351 treatment and you know, it stabilised things and I wasn't *- getting to a deadline*  
352 well enough to work but I was well enough to, you know *- it passed*  
353 potter around the house and do stuff. So I got used to that, *- getting unwell*  
354 but then you're thinking, 2-3 years is coming up you know, *- leg breaking*  
355 what's going to happen now but, it passed, the 2-3 years *- (spot of cancer)*  
356 passed but then I started to feel a bit more unwell and have *- had been*  
357 more pain. That's when my leg broke, so my leg broke *- having check-ups*  
358 [laughs] which was spot of cancer up here, but while I was *-*  
359 in with my leg having broken, even though I've been having *-*  
360 scans, I had a scan less than 3 months before I broke my *-*  
361 leg, when I was in with my leg they said, oh your blood's

54  
incurable  
cancer -  
surpassing  
deadline  
-uncertain  
-the  
awful  
bit of  
not  
knowing

• Felt important for her to tell her story!!

Picture 3: Example of post-sort interview transcript.







**Picture 6: Factor array for factor three and table examining statements in factor three that were ranked higher or lower than in other factors.**

## Appendix D: Personal Q-sort

-6	-5	-4	-3	-2	-1	0	1	2	3	4	5	6
61	43	38	29	22	20	14	41	8	3	52	33	55
49	47	48	20	60	62	16	8	16	1	19	53	21
	34	28	36	25	5	45	2	18	35	17	57	
		46	56	42	51	15	18	38	11	54		
			32	39	7	27	44	56	12			
				6	13	50	58	62				
						59	23	26				
							24					

## Appendix E: Reflection on Theories of PTS and PTG

POST TRAUMATIC GROWTH	Has this been present within my own experience of living with a physical health problem?
Enhanced appreciation for life	N
More meaningful interpersonal relationships	Y- Closer to my family and partner as a result of physical health problem
Enhanced sense of personal strength	N
Altered priorities	N
Richer existential and spiritual life	N

POST TRAUMATIC STRESS	Has this been present within my own experience of living with a physical health problem?
Intrusion (re-experiencing of the traumatic event)	Y- Have experienced nightmares related to loss of vision/surgical procedures
Avoidance of trauma related stimuli	N
Negative changes in cognition and mood	N
Arousal and re-activity	N

Reflecting on how the descriptions of PTS and PTG have resonated with my own experience of illness was beneficial. It enhanced my awareness of the parts of these constructs (PTS and PTG) that I may more readily notice within the analysis.



## Appendix F: Example Post-interview Reflection

After examining the stories told by each factor, I was able to consult my reflective diary. This allowed me to ensure that my interpretation of their data was consistent with their presentation during participation, and remained as close as possible to their reported experience.

Reflective Account for P7
<b>Recruitment notes:</b> P7 asked few questions about the study, and appeared to understand the premise of it. She reported being keen to participate but found it difficult to commit to a time/date as her husband was unwell. I did not gather data from her until two months after her opting-in to the study
<b>Study Location and description:</b> I visited P7 in her home and the study was conducted in her conservatory in front of a small table. The room seemed very calm, and was incredibly quiet (other than ticking of clocks).
<b>How did P7 present:</b> She spoke very quietly and slowly, and appeared as very calm. She was tearful at various intervals, but also laughed when recounting memories about x and her husband. Her mood seemed low and hopeless
<b>Interactions with the Q-Set:</b> P7 did not ask any questions about the Q-set, and reported that she understood the task. She did not show any strong reactions to any of the statements (was only tearful in reflective discussion).
<b>Representativeness:</b> P7 felt that she could communicate her experience effectively through the Q-statements. She could not think of any statements to add.
<b>Key observations:</b> P7 was tearful at times throughout our discussions. She was keen to discuss the story of her husband's illness, and how they had managed this as a couple. She knew all the details of her husband's AC, the dates that he was diagnosed, what treatment he had been given, and how successful it had been. She was deeply saddened by his experience. She clearly held a genuine concern for his well-being and talked with compassion and empathy about his "pain and suffering". In particular, P7 seemed to enjoy talking about memories of the things that she and her husband have done since his diagnosis. She smiled when discussing these and said that she was glad to have such memories. P7 seemed to be stuck in limbo, unable to do anything, plan anything, or look forward to the future. She discussed being unable to engage in the things that they had done in the past and I got the sense that her husband's diagnosis of AC had really impacted on every aspect of their lives (e.g. their relationship, their future plans, they day to day activities). In saying good bye to one another P7 was very appreciative. She thanked me for listening to her.
<b>Did she perceive there to be any benefits to AC?</b> No. P7 stated with certainty that she had not felt any benefit to caring for someone with AC.
<b>Did she perceive AC to be traumatic?</b> Yes. P7 has found this

experience very upsetting. At one stage in the study, she said that it has been “traumatic”.

**Own feelings in the room with P7:** I felt very sad and heavy in the room with this participant. I also felt isolated from the outside world, cut off, as if time had stopped. When I walked into her house, it felt like the world outside did not exist. I attempted to prompt and clarify her responses when she was upset, monitoring her to ensure she did not become too distressed, but asking questions that were necessary for me to understand her story. I felt incredibly appreciative of P7 sharing her stories with me and was impressed at her willingness to be vulnerable and open to a complete stranger.

## **Appendix G: 'Self as a Researcher' Formulation**

I believe being an effective and safe practitioner involves having a sound awareness of oneself. My 'Self as a Practitioner' formulation has helped me to identify my responses (and actions) which impede my ability to be an effective Psychologist. Similarly, developing my 'Self as Researcher' formulation has enhanced my recognition of my feelings in response to the research process that could impact on my ability to be an effective researcher in the future.



**Early Experiences**  
Both grandmother and mother worked as nurses. They worked long hours and enjoyed taking care of others. Grew up in a very large family in which there were lots of younger children, whom I was often encouraged to take care of. Diagnosed with degenerative visual health problem at age 14. Recall my parents being upset about this news. Attended a competitive school and recall being under pressure to achieve high results.



**Beliefs**  
I'm not good enough  
Others are vulnerable  
The world is unfair



**Conditional Assumptions/Rules**  
If I work incredibly hard, then I will be good enough.  
If I remain aware of my own short comings, then I will be good enough.  
If others are in distress, I must take care of them.  
I should always protect others.  
I must always put in 110%.



**Compensatory Strategies**  
Being self-critical and attacking of my own efforts.  
Working incredibly hard to ensure high standards are met.  
Looking for short comings and attempting to correct them.  
Avoiding causing others any distress.  
Protecting others.



**Critical Incidences:**  
Transitioning into becoming a researcher. Carrying out research in the area of palliative care.



SITUATION	SITUATION	SITUATION
Writing up my study. Making decisions or facing general uncertainty.	Interviewing my first participant.	Listening to stories of illness and death
THOUGHTS	THOUGHTS	THOUGHTS
I am concerned that X is wrong; I need to understand X more; I have struggled to commit to a review topic; May be I could be doing something different to boost recruitment.	I felt concerned about pushing her; What if I caused her to become upset; I was concerned she'd feel sad and would be on her own after the interview	I was struck by how unlucky she had been; I wondered how she was able to get through each day, even with feeling so drained and scared; In listening to how her partner had supported her...I was reminded of how supportive my own partner had been.
FEELINGS	FEELINGS	FEELINGS
Anxious	Apprehensive	Sad. <b>Enlightened.</b> <b>Impressed</b>
MEANING OF THOUGHT	MEANING OF THOUGHT	MEANING OF THOUGHT
I will fail	She won't cope.	Life is about luck. <b>Life is precious.</b>
BEHAVIOUR	BEHAVIOUR	BEHAVIOUR
Ruminating over small decisions. Reading an excessive amount. Taking too long on tasks.	Excessive worry about participant becoming upset.	<b>More appreciative of my own life, and of my family.</b> <b>More accepting of uncertainty.</b>



