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Doctoral Thesis

Cancer: Emotional Experiences

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Word Count

	Main text	Appendices (inc. tables, references, abstracts, footnotes and title pages)	Total
Thesis Abstract	279	0	279
Literature Review	7,809	6,084	13,893
Research Paper	7,844	3,263	11,107
Critical Appraisal	3,372	371	3,743
Ethics Section	5,912	1,442	7,354
Total	25,216	11,160	36,376

Thesis Abstract

Cancer can have major implications for those who receive a diagnosis, not only as a result of its physical impact, but its emotional one. The emotional impact can not only be distressing in itself, it can also affect behaviour and therefore, has been linked to poorer treatment adherence.

The experience of difficult self-directed emotions, such as guilt, shame and disgust have provoked particular interest, particularly due to their association with rejection and avoidance. Therefore, insight into how and when these emotions are experienced within the cancer treatment journey are important to understand, in order that optimum support can be provided.

The first paper is a thematic synthesis that explores the emotional experiences of people undergoing cancer treatment with a curative intent. The synthesis is structured by a sequential framework of four key transition points within the cancer journey, and the emotional experiences synthesised within each one. The temporal transition points were: Being diagnosed and facing treatment; Getting rid of cancer; Changed body and stigma; Reflections on the emotional journey having completed treatment. The synthesis demonstrates how emotions and feelings evolve and change in type, frequency and intensity across the curative cancer journey.

The second study uses narrative analysis methodology to explore difficult self-directed emotions throughout cancer treatment and into recovery. The analysis focuses on how and when the emotions of disgust, guilt, shame and fear arise, as well as resulting changes to the sense of self. The findings demonstrate how many factors, such as relationships, current stressors, past experiences and resources (personal and systemic) can impact on emotional

experiences. The critical appraisal focuses on strengths and weaknesses of the studies, particularly in relational to emotional research considerations more generally.

Declaration

This thesis documents research undertaken between September 2016 and November 2017, in partial fulfilment of the Lancaster University Doctorate in Clinical Psychology. The work presented here is my own, except where due reference has been made. This thesis has not been submitted for the award of a higher degree elsewhere. The word length of the thesis conforms to the permitted maximum.

Signature:

Print name: Selane Rigby

Date: 10/11/17

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I offer every depth of gratitude to my long suffering family and friends, who have kept me grounded throughout the sometimes arduous process of writing a thesis. In particular, I want to thank Charlotte and Ella, who have offered me constant reminders of the important things in life. I can only hope that I too can offer the same during their future academic endeavours.

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Thesis Section 1: Thematic Synthesis

A thematic synthesis of the emotional experiences throughout the cancer treatment journey.

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Intended journal - Psychology & Health

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Abstract

Aim: In an attempt to understand the emotional experience of people undertaking cancer treatment (regardless of any formal ‘mood’ diagnosis), a qualitative synthesis was undertaken.

Method: The search strategy was designed to include international research from the perspective of the individual undergoing treatment - from cancer diagnosis to the completion of curative treatment, including adjuvant therapy. The thematic synthesis was conducted according to the framework set out by Thomas and Harden (2008).

Findings: The search strategy yielded an initial set of 7,093 papers from which, after the inclusion and exclusion criteria were applied, 12 were retained for analysis. The analysis produced four temporally organised themes that spanned a diverse range of cancer experiences: Being diagnosed and facing treatment; Getting rid of cancer; Changed body and stigma; Reflections on the emotional journey having completed treatment.

Discussion: The synthesis demonstrated how emotional experiences are related to coping strategies and ultimately the adoption of new identities. Social comparisons were used in order to gain and maintain hope and to cope. However, gender differences in how emotional experience was expressed and acted upon were also illustrated. The findings are discussed in relation to the complexity of emotions and how they evolve across the cancer treatment journey.

Keywords: Cancer, Emotions, Experiences, Thematic Synthesis

It is predicted that by 2035 approximately 24 million people worldwide will have had a cancer diagnosis (World Cancer Research Fund International, 2016). Despite the increase in the number of people receiving a diagnosis of cancer, mortality rates are falling. This trend can particularly be seen in countries such as the United Kingdom where there have been significant advancements in detection and treatments (Office for National Statistics, 2015). However, regardless of increasing survival rates, cancer remains a life-threatening illness affecting people not only physically, through the disease process and treatment effects, but emotionally, throughout the cancer journey.

Many studies have been undertaken to explore specific aspects of having cancer, for example, the experience of being diagnosed with a particular type of cancer at certain stages, such as advanced lung cancer (Dickerson et al., 2012). Other studies have focused on the experiences of cancer diagnosis from a cultural (Ashing-Giwa et al., 2004) or family relative perspective (Olson, 2011), and demonstrate the emotional impact of cancer. Moreover, studies that have concentrated on the experience of undergoing specific cancer treatments, such as chemotherapy (Bernhardson, Tishelman, & Rutqvist, 2007) or focused on the treatment of side-effects such as alopecia (Williams, Wood, & Cunningham-Warburton, 1999), demonstrate a wide array of emotional experience. Furthermore, a number of studies have focused on the emotional experiences across the whole cancer treatment journey with curative intent.

Theoretically, it has been proposed that there are six emotions (happiness, fear, anger, sadness, disgust, sadness and surprise) (Ekman, 1992), with all other emotions considered to be a combination of these basic emotions (Plutchik, Kellerman, & Conte, 1979). Feelings, however, although considered closely related to emotions, differ from them on the basis of being mental associations to emotions that are autobiographical and influenced by personal experiences and beliefs (Damasio, 1999). The term affect is often used to describe the experience of feeling or emotion (VandenBos, 2007). Lay understandings of the 'emotional' experiences of being diagnosed with cancer and receiving treatment may incorporate both or a combination of different affective experiences throughout the treatment journey. In this regard, the term emotional experiences in this review is more encompassing and is used to describe not just emotions but feelings, which encompass personal appraisals and labels (Shouse, 2005). Using this broad definition of 'emotional experience' means that all personal affective experiences (emotions and feelings), such as emotional distress and problems are included with the analysis.

The interest in emotional experiences is in part due to the frequency of emotional difficulties experienced by people with a cancer diagnosis. For example, one study in North America estimated the prevalence of emotional distress to be 35.1% overall (Zabora, BrintzenhofeSzoc, Curbow, Hooker, & Piantadosi, 2001), with similar rates reported in Europe, Asia and the Middle East (Bultz & Carlson, 2005). These high prevalence rates of distress experienced within the cancer journey have led to emotional distress being considered by some cancer researchers as 'the sixth vital sign in cancer care' (Bultz & Carlson, 2005, p. 1).

Emotional distress is associated with increased costs in cancer treatment care, due to a documented relationship between distress and treatment adherence. For example, a systematic review of psychosocial treatments for emotional distress in cancer concluded that large reductions in medical costs (from general practitioner and specialist visits) could result from treating 'emotional problems' (Carlson & Bultz, 2003). Emotional distress, such as anxiety symptoms have also been found to predict reductions in chemotherapy adherence (Greer, Pirl, Park, Lynch, & Temel, 2008).

A focus on emotional distress and its consequences has been responsible for shaping guidance on the identification and subsequent interventions for these types of emotions during cancer treatment (National Cancer Control Initiative, 2002; National Institute for Health and Clinical Excellence, 2004; World Health Organization, 2002). The underlying assumptions of emotional distress are that these experiences are negative. As a result, the guidance is focused on the management of distress, viewing it as requiring early identification and intervention from the point of diagnosis and throughout the treatment journey.

However, the assumption that the experience of distress is purely negative, and therefore needs treating, is not unchallenged. For example, a study which adopted a qualitative methodology to understand emotional distress soon after a cancer diagnosis demonstrated that attempting to engage people psychologically, early in their cancer journey, may not only be unhelpful but may disrupt their own individual styles of coping (Baker et al., 2013). Moreover, some evidence suggests that experiencing emotional distress can actually be of benefit, with some studies finding that early emotional distress can be indicative of ‘positive adjustment’ later in the cancer journey (Arman, Rehnsfeldt, Lindholm, Hamrin, & Eriksson, 2004; Horgan, Holcombe, & Salmon, 2011). Similarly, some evidence has indicated that emotional suppression soon after cancer diagnosis is linked to increased distress and ‘poorer adjustment’ in the future (Iwamitsu et al., 2003; Stanton et al., 2000). Therefore, emotional distress during cancer treatment requires more complex interpretations and understanding than viewing the experience through an inherently undesirable lens.

In contrast to the distress narrative that dominates much of the empirical and grey (unpublished or published non-commercially) literature, positive emotional and psychological changes have also been demonstrated as part of the cancer journey. Some of this research focuses on psychological well-being within the cancer journey as measured through the absence of negative affective experiences, for example, depression (Kissane et al., 2004), anxiety (Segrin, Badger, Dorros, Meek, & Lopez, 2007) and trauma (Cordova et al., 2007) symptoms. However, some studies have also demonstrated positive affective changes throughout the cancer journey, such as, after diagnosis (Horgan et al., 2011) and in the late-stages (Rabkin, McElhiney, Moran, Acree, & Folkman, 2009). For example, a qualitative review of 57 studies (35 of which focused on cancer) assessing post-traumatic growth in life threatening illness (Hefferon, Grealy, & Mutrie, 2009) found positive longer term changes as a result of having this type of illness. The review demonstrated that people re-evaluated their relationships, leading to closer and more open relationships with close family and friends, had less interest in appearance and monetary wealth and experienced a change in life goals. Many people also gained a sense of physical power and potency and reconnection of the body and mind.

Many policies and protocols within the area of distress management rely on health professionals to undertake screenings at time points within the cancer treatment journey. However, some studies have indicated that the understanding of events that cause distress differs between health professionals and people with cancer. For example, a qualitative study sought to identify events that caused distress in women with breast cancer and compared these with physician expectations of events to cause distress. Although there was concordance in some events, such as diagnosis, many women expressed distress at the side-effects of treatment and problems with prosthesis after mastectomy, which were not reflected in physicians' expectations (Jones & Greenwood, 1994).

To attempt to understand the emotional experience from the perspective of the person undertaking cancer treatment (regardless of emotion/mood classifications) - a methodology that can capture the complex nature of the emotional experience of the cancer journey is required. Qualitative studies can uncover emotions and meaning and explain the processes of emotional change that may be experienced within the cancer treatment journey (Dixon-Woods, Fitzpatrick, & Roberts, 2001). Thematic synthesis is a method by which a body of qualitative studies can be drawn upon in order to offer an understanding of a given experience (Thomas & Harden, 2008) - in this case the emotional experiences within the cancer treatment journey. Thus, thematic synthesis is an approach that can provide a broad description by drawing on many themes from which interpretative constructions and understandings of emotional experience of the curative cancer treatment journey can be formed. Thematic-synthesis can also be conducted from a critical realist stance, in which the possibility of objective knowledge or reality is accepted, while maintaining that many different meanings and interpretations of a phenomenon can co-exist (Barnett-Page & Thomas, 2009). Furthermore, qualitative research is becoming more and more utilised in health settings, with health professionals incorporating findings from these studies into their practice (Miller, 2010).

Method

Identification of Published Work

In October 2016, a systematic literature search was performed across PsycINFO, CINAHL (Cumulative Index to Nursing and Allied Health Literature), PubMed and Web of Science. The PsycINFO, CINAHL and PubMed databases provide good coverage of the subject matter and have been used in previous reviews that focused on the experience of cancer (e.g., Smith, Pope, & Botha, 2005; LeSeure & Chongkham-ang, 2015). In addition, Web of Science was included as it provides a broad subject search that includes health and medicine, social sciences and arts and humanities potentially relevant to this thematic synthesis. Guidance and advice on the search strategy was sought and provided by an academic librarian from Lancaster University.

The review included papers from peer-reviewed journals and those which met the inclusion and exclusion criteria (LeSeure and Chongkham-ang, 2015, was also used for guidance):

1. Studies that were based on a population of adult participants 18 years or older when diagnosed with cancer.
2. Studies that focused on emotional experiences from diagnosis through to completion of active curative treatment.
3. Studies in which the researcher(s) obtained and presented interview data from people with a cancer diagnosis separately from any other samples included in the research paper.
4. Data based on the emotional experience of cancer patients were presented.
5. Studies that used qualitative content-based (as opposed to discourse-based) methodologies for data analysis.
6. Mixed-design studies which separately analysed and presented qualitative findings from quantitative data and used content-based approaches such as grounded theory, interpretative phenomenological analysis, hermeneutics, thematic analysis, content analysis and narrative analysis.

Studies were excluded if:

1. The population within the study were no longer undergoing curative treatment, such as terminally ill patients, or those receiving end-of-life care, or those only receiving supportive treatment, as this was considered a qualitatively different experience from curative treatment (LeSeure & Chongkham-ang, 2015).
2. Studies that focused on specific experiences of cancer, as the full emotional experience from across the cancer treatment journey could not be illustrated. Specific experiences included a focus on symptoms, such as cancer related pain (e.g. Boström, Sandh, Lundberg, & Fridlund, 2004) or lymphedema, (e.g. Johansson et al., 2003) or specific cancer

treatment experiences, such as chemotherapy (e.g. Bernhardson et al., 2007), or cancer related inventions, such as, relaxation (e.g Adamsen, Stage, Laursen, Rørth, & Quist, 2012) or psychoeducation (e.g. Edelman, Craig, & Kidman, 2000).

3. Papers that focused on phases before or after cancer treatment, such as survivorship or screening.

4. Studies that focused predominantly on relationships or sexual well-being of cancer patients, or focused on aspects of communication.

5. Papers that focused on one experience within the cancer treatment journey, such as diagnosis or hope, as the focus was not on the breadth of emotions spanning the treatment journey.

6. Papers that did not support themes with direct quotations.

7. Studies that did not use an established qualitative design.

8. Reviews and editorials, as per Smith et al. (2005).

9. Due to difficulties in the translation of 'meaning' across languages, non-English language papers were excluded (Temple, 2006).

Search terms were generated using past literature reviews within the cancer research domain (LeSeure & Chongkham-ang, 2015). MESH or thesaurus headings were exploded when possible and subject headings incorporated. Where possible, a methodology filter was applied (Search Filter for Databases, The University of Texas, 2016). When this was not possible, specificity filters for methodology within the search engine were applied (see Appendix A for exact terms input for each database search). The search terms used were 'neoplasms' OR 'oncology' OR 'cancer' AND 'emotion*' OR experience*' OR 'perception*' AND 'individual*' OR 'client*' OR ' patient*' OR 'cancer patients' AND 'interviews' OR 'focus groups' OR 'narration' OR qualitative research OR' semi-structured' OR 'semistructured' OR 'unstructured' OR 'structured' OR 'informal' OR 'in-depth' OR ‘indepth’ OR ‘face-to-face’ OR ‘guide’ OR ‘guides’ AND ‘interview*’ OR ‘discussion*’ OR ‘questionnaire*’ OR ‘focus group’ OR ‘focus groups’ OR ‘qualitative’ OR ‘ethnograph*’ OR ‘fieldwork’ OR ‘field work’ OR ‘key informant’.

Selected studies

The details of how the identified papers were included in the thematic synthesis are contained within Figure 1. From the search strategy, 12 papers were identified that met the terms of criteria and are detailed in Table I.

[INSERT FIGURE 1 HERE]

[INSERT TABLE 1 HERE]

Characteristics of the selected studies

The 12 identified studies were published between 2000 and 2016. Of these, six used European samples (3 in the United Kingdom, 2 in Sweden, 1 in Finland). Two studies used Australian samples, two used US samples, and two used a sample based in Iran. The sample size used within the studies ranged from 5 to 45. The mental health status of participants was not indicated in the studies reviewed.

All the papers used a content-based qualitative analysis to analyse the data. Three used a thematic analysis method, three used content analysis, four used a phenomenological approach, one a hermeneutic method and one employed grounded theory.

Nine papers used face-to-face interviews for data collection, with two studies (Oster, Hedestig, Johansson, Klingstedt, & Lindh, 2013; White-Means et al., 2015) using focus groups. One study used semi-structured written narratives across two time points, one week and three months post-yoga intervention (Leal et al., 2015). Although the exact length of time elapsed since cancer diagnosis and the completion of treatment was not always clear, the stage within the treatment journey was able to be ascertained by careful reading of the analysis and participant quotations provided. All papers focused on experiences from diagnosis through to treatment as a minimum, but as a set of papers the interviews covered experiences that ranged from pre-diagnosis through to convalescence following treatment.

Appraising the quality of reporting of the selected studies

The strengths and weaknesses of reporting for each study were considered using the CASP checklist of qualitative studies (Critical Appraisal Skills Programme, 2017). The initial items in the checklist related to whether there was a clear statement of the research aims and if a qualitative methodology was an appropriate approach given the intended aims. All the selected studies met these criteria. Each paper was then evaluated by the researcher across the remaining eight items on the qualitative study checklist. A three point system was used for each of the eight checklist items which generated a score for each component (Duggleby et al., 2010). Scores between one and three corresponded with whether the reporting for the area was considered weak, moderate or strong. A total for reporting strength, out of a possible 24, was then generated for each paper (see Table II).

[INSERT TABLE 2 HERE]

Analysing and synthesizing the data

Qualitative synthesis is valued, particularly within health research, for its ability to offer explanations for qualitative study findings. However, how the quality of the studies used in qualitative reviews is assessed and even if quality assessment offers any utility is still debated, particularly when considering study quality in review exclusion versus inclusion criteria (Dixon-Woods et al., 2001). Furthermore, some researchers in the field of health research have opted to use an entirely inclusive approach. The rationale for this type of approach has been based on previous experience of using such tools as the Critical Appraisal Skills Programme (CASP), coupled with the argument that papers used in the subsequent review should be judged on how much they contribute to the synthesis question (Smith et al., 2005). In this respect, Thomas and Harden (2008) offer an approach to synthesising qualitative studies that discourages preconceptions of objectivity, instead highlighting subjectivity, and therefore can be seen as an interpretative, as opposed to an aggregative, approach. For the purpose of this review, CASP was used in order to highlight the quality of reporting, however it was not used to exclude papers from the review.

This thematic-synthesis utilised a seven-phase approach that incorporated Thomas and Harden (2008) three stage synthesis. The initial phase involved finding a review question that incorporates both the intellectual interest of the researcher and requires a strategy by which ‘how’ or ‘why’ questions could be answered. The subsequent phase involved making decisions around what was relevant in order to answer the question. Particular to this synthesis, studies that focused on people who were undergoing a curative cancer treatment journey were relevant, therefore the studies of interest for comparison needed to involve perspectives from people with this particular lived experience and foregoing other experiences, such as those of care-givers. Applying particular inclusion and exclusion criteria avoided the synthesis becoming too generalised and ensured an original account.

The analysis of the identified data for synthesis began in the third phase by reading and re-reading the selected accounts, drawing on the details held within findings or results sections of studies and how they related to the research question. The data included themes, interpretations, sentences and participant quotes that related to emotional experience (see Appendix B, for a sample data extraction table). In particular, the focus was on emotional experience, in relation to what these experiences were and the points at which they were being experienced within the cancer treatment journey. Leading on from this, the fourth phase of the analysis began to bring together findings from across studies, by creating a list of emotions and when they occurred. As a result, a thematic analysis was formed and initial assumptions of how individual studies related to each other began to be identified and developed. During this phase, it was noted that many themes across the studies fell into temporal or sequential sections that acted as transition points within the curative cancer treatment journey. In fact six of the studies themes were ordered sequentially as the cancer treatment trajectory unfolded (Hu, Cooke, & McCarthy, 2009; Papadopoulou, Johnston, & Themessl-Huber, 2016; Taleghani, Yekta, Nasrabadi, & Kappeli, 2008; White-Means, Rice, Dapremont, Davis, & Martin, 2015; Winterbottom & Harcourt. 2004; Xuereb & Dunlop, 2003). At this point a general sequential framework was adopted in order that emotional themes from each of these transition points within the journey could be illustrated. (Heiland et al., 2008)

Phase five involved translating the central emotional experience of each account and their interactions, and comparing them to the accounts and interactions across the studies, within each part of the treatment experience. Particular attention was given to data diversions within the themes. How well the concepts incorporated the themes from the original studies was evaluated and adjustments made in order to capture the accounts from each paper (see Appendix C, for a sample of a grouped concept).

Translation of the studies then led to synthesis in phase six. The synthesis phase involved answering the review question with analytical themes created utilising the emerged themes from the inductive analysis of studies. The analytical themes capture a key concept or ‘line of argument’ (Thomas & Harden, 2008, p.7) related to the review question and from which recommendations can be generated. The contribution per paper towards the themes was noted (see Table. III).

The final phase of the analysis was concerned with how synthesis was expressed. In this regard the synthesis needed to be understood, while being meaningful. Moreover, the synthesis needed to stretch the insight of its intended audience, by presenting the views and perspectives of those experiencing the cancer treatment journey.

The data were analysed based on critical realist epistemology, in that the analysis accepted that it is possible to know individual perspective, as thoughts, feelings and experiences are reflected in the language of the participant.

[INSERT TABLE 3 HERE]

Findings

The thematic synthesis concerns the emotional experiences within these four temporal themes: Being diagnosed with cancer and facing treatment; Getting rid of cancer; Changed body and stigma; Reflections on the emotional journey having completed treatment.

Being diagnosed with cancer and facing treatment

The emotions experienced at the point of being diagnosed with cancer were wide ranging and included fear, worry, hope, sadness, disappointment and uncertainty. These mixed feelings were typically experienced in quick succession and changed rapidly: ‘Everything was chaotic, and I didn’t have one clear thought in my head’ (Ekman, Bergbom, Ekman, Berthold, & Mahsneh, 2004, p. 179). All studies with the exception of one (Joulaee, Joolaee, Kadivar, & Hajibabaee, 2012) reported that shock was the initial reaction to receiving a diagnosis of cancer, despite participants experiencing bodily symptoms consistent with a potential diagnosis.

Feelings of fear and worry were demonstrated in all papers; in particular these feelings were related to the potential threat to life that a cancer diagnosis posed and highlighted visceral responses: ‘I felt like my guts had been ripped-out. I was going to die and I was definitely not ready for it.’ (Leal et al., 2015, p. 141). This physical response to diagnosis vividly indicates the depth and intensity of the emotions experienced at this time. However, two papers noted that whether and how people had been previously exposed to cancer, appeared to influence the perception of cancer as a ‘death sentence’ (Ekman et al., 2004; Winterbottom & Harcourt, 2004). Participants who had previous experience or knowledge of cancer saw their tumour as a disease that could be treated:

> Um…obviously when they told me it was cancer, the big ‘C’ word, it was scary…but I was still quite calm, because I was told that it was 0.6 mm. And if it’s over 1 mm, that’s when it’s got the potential to spread. So I was still quite calm and I thought, ‘Oh well, you know, we’ve caught it early enough, I’m not too worried’. (Winterbottom & Harcourt, 2003, p. 230)

After the initial shock, previous experiences of cancer survival led to more readily expecting a cancer diagnosis with bodily signs such as ‘hard belly’ or urinary incontinence being viewed as potential indicators of cancer. Furthermore, some participants reported that they had strong thoughts and feelings connected with cancer, such as feeling like there was a ‘spider in the body’ before receiving a cancer diagnosis. These thoughts and feelings indicated the emotion of disgust resulting from the feeling contaminated by the harbouring of the unwelcomed cancer. Both these scenarios offered some buffering against the shock and surprise of receiving a cancer diagnosis ‘So it was not a big surprise. In some strange way I knew what it was’. (Ekman et al., 2004, p. 179).

In contrast, those informants who had no previous experience of cancer and therefore were reliant on dominant perceptions of cancer, or those who had negative cancer experiences, such as cancer leading to the death of a close relative, friend or spouse, tended to think of their diagnosis as a death sentence. Those people who felt their diagnosis was potentially ‘the end’, experienced fear, panic, distress and turmoil, which one participant expressed as a ‘special kind of anxiety’ (Taleghani et al., 2008, p. E35). Experiencing these emotions for some led to expressions of needing to feel ‘strong’ indicating defiance and a need for courage, in order to fight their cancer and alleviate the threat to life. Experiences of needing to feel strong and preparedness to fight by getting on with the treatment was reported in four papers. One participant expressed this as ‘attack mode’ leading to a desire for immediate action, asking ‘How soon can we get it out?’ and expressing that ‘If I could’ve had my surgery the next day, I would have’ (White-Means et al., 2015, p. 10). Moreover, there was a need to escape as a response to the emotional turmoil of receiving a cancer diagnosis:

> I felt like I had done a crime and I was waiting for the verdict to be handed in . . . I did contemplate suicide . . . and it is only my strong maternal instinct that kept saying ‘no, it was more heroic to die of cancer than going under a train’. (Xuereb & Dunlop, 2003, p. 401).

Both expressions of needing to fight or to escape were responses to the emotional experience of receiving a potentially life threatening diagnosis. Both offered attempts to gain some sense of control during a time of uncertainty.

Furthermore, social comparisons were used as a way of gaining a more positive perspective on the diagnosis, by concluding that the situation could have been much worse. This was demonstrated in three papers: ‘I just thought, you know, it is one of those things, that it’s been noticed and it’s being treated’ (Winterbottom & Harcourt, 2004, p. 230). Moreover, concern over the impact of the cancer diagnosis on family members, was prioritised over personal emotional distress in seven studies: ‘It’s better they don’t worry I mean the wife and the children, too’ (Vaartio, Kiviniemi, & Suominen, 2003, p. 184). The possibility of dying led to concern for important people in participants’ lives: ‘The only thing that went through my head was “I will not see my beautiful daughter walk down the aisle”. There was no concern for me, that was one thing I wanted to fulfil.’ (Xuereb & Dunlop, 2003, p. 400).

Waiting for cancer treatment, treatment procedures and the treatments themselves elicited many different emotional experiences. However, a common factor was the urge to want to rid the body of cancer as soon as possible. Cancer was viewed as a dangerous contaminant within the body that posed a greater threat the longer it remained there: ‘Cancer is something ‘evil’ that should be removed from the body’ (Ekman et al., 2004, p. 179). Therefore waiting for cancer treatment to begin was a difficult period with much uncertainty. However, once arrangements for active treatment began, feelings of hope and an impetus to defy cancer emerged: ‘Up until I had the transplant there was no hope, and without any hope I didn’t have anything to really work towards. But once I started to get some hope, you know, the fight began.’ (Xuereb & Dunlop, 2003, p. 404).

In contrast, some cancer journeys that involved treatment immediately after diagnosis, such as that for people with malignant melanoma (White-Means et al., 2015), did not involve a period of waiting. However, feelings of gratitude, relief and happiness that treatment swiftly followed diagnosis, along with empathy for how difficult waiting may have been, were expressed:

> I think I am a bit of a coward myself, and if I would have had to go home and wait I am not quite sure whether I would have made it back. So I am glad that it was done on the day. (Winterbottom & Harcourt, 2004, p. 231).

A common response to uncertainty while waiting for treatment to begin was to attempt to prepare for all eventualities, including the prospect of leaving loved ones behind. Some used this waiting time to ‘get their house in order’ (France et al., 2000, p. 344), making legal and practical arrangements in order to alleviate concerns for family members. The responses adopted to the uncertainty and worry experienced during this period of waiting helped participants gain some sense of control at a time when treatment progress was in the hands of others.

Getting rid of cancer

The wide variation in treatment processes elicited many emotional experiences in those undertaking them, from fear that the treatment would be difficult and potentially unsuccessful, versus the hope that it would rid the body of cancer and lead to a cure. However, much of the action towards a cure was in the hands of clinicians and is therefore reliant on trusting empowered professionals. In order to manage the distress caused by finding themselves in a disempowered situation, different strategies were used. Some managed this distress by finding reassurance in the skills of the surgeon and even, where possible, choosing their surgeon.

In contrast, the experience of being in the hands of others left some feeling coerced and lacking a sense of control or agency during exposing medical procedures. '. . . and they took that prostate and fired eight shots at me. Oh, oh, that was not good, I think.' '[It was like] . . . rape.' (Oster et al., 2013, p. 334). 'They took' as well as 'rape' indicates an enemy analogy, with the health professions undertaking the treatment in a position of power and control. The word 'rape' also suggests violation and its use within this context may be a projection of the original violation of cancer. Others found that a lack of control and distress stemmed from the 'foreignness' of the hospital culture, being part of an unfamiliar system at a time of vulnerability and when feeling anxious: 'Cancer and treatments are usually foreign situations to deal with, and people assume that you know more than you do, or that someone else has talked to you, it makes it even more difficult.' (Leal et al., 2015, p. 142).

Furthermore, the hospital stays during curative treatment served as both a source of comfort and distress. Some experienced the hospital environment as a signal of hope for the future, seeing it as a place of security. However, particularly for those facing extended hospital stays due to the nature of their treatment, such as transplant patients, the restrictions placed on them were sources of distress. One participant likened the experience to imprisonment: 'Feels like a trapped insect trying to find its way out by crawling up the walls of confinement to freedom'. (Papadopoulou et al., 2016, p. E76).

Moreover, medical professionals were viewed by some participants as a potential source of comfort and reassurance, particularly when experiencing difficult emotions such as embarrassment or fear. Calm talk and sharing experiences of recovery were viewed as positive responses by professionals to the difficult emotional experiences of people undergoing treatment. In contrast, feelings of fear and distress could also be enhanced if medical staff in control, did not acknowledge or attend to them, particularly when undergoing medical procedures and attempting to respond to instructions.

> Because I thought, ‘can’t they see how hard this is? This is really, really hard’. When you’re feeling so bad . . . they were actually trying to do me a favour, but maybe they didn’t understand the level of effort I was making. (Xuereb & Dunlop, 2003, p. 404).

Adjuvant therapy, such as chemotherapy, could elicit strong emotions, particularly when many of the side-effects induced physical and psychology changes. For some, particularly those for whom their cancer had remained invisible, due to little change to the body envelope as a result of surgery or few symptoms prior to treatment, bodily changes as a result of chemotherapy could result in cancer feeling closer or more real than before. The side-effects of chemotherapy were lengthy and typically involved: fatigue, hair loss, nausea, vomiting, heartburn, and stomach pain, often coupled with anxious feelings. A common theme resulting from receiving chemotherapy was that this was the most difficult part of the cancer treatment journey to manage: ‘The treatment they give me, it is barbaric. Cause I was so sick . . . I knew it was going to be bad, but I didn’t realise how bad it was’. (Xuereb & Dunlop, 2003, p. 404). This part of the treatment journey, particular as a result of fatigue, could lead to feeling low and not in control: ‘You kind of get depressed or something and you just want to lie there and sleep to get rid of it.’ (Vaartio et al., 2003, p. 185)

However, although the side-effects of the treatment had a negative impact, both physically and psychologically, the enormity of the changes resulting from chemotherapy could elicit feelings of hope. Chemotherapy could be viewed as a ‘good poison’ that could ‘cleanse’ the body of cancer: ‘It must be something very strong in the medicines in that you feel so sick, but it will surely take away the cancer cells.’ (Ekman et al., 2004, p. 179).

In comparison to chemotherapy, radiotherapy resulted in fewer side-effects due the nature of the treatment. However, strong emotions about the therapy were particularly salient at the time that the treatment was administered. These emotional experiences included embarrassment and feeling unsafe. In particular, the process of being examined in order for the radiotherapy to be correctly aligned to the target area was considered embarrassing. The treatment then requires that the person undertaking the therapy remain completely still and alone for number of minutes. This experience was often accompanied with feelings of uncertainty and isolation:

> The first time when I was lying there I felt excluded [from knowing what was happening] . . . preferably you would like to see it [the radiation equipment], pick it to pieces, oh . . . that would alleviate the pressure of that feeling of not knowing. (Oster et al, 2013, p. 334).

However, a sense of hope and feeling lucky to have therapy that would lead to recovery was also felt at this time.

Changed body and stigma

As a result of some surgical treatments, the body was affected. Commonly, changes to the body envelope caused a huge amount of distress. The impact of changed body image had the capability of penetrating many areas of the person’s life, including intimate relationships, career and social life. More notably, change in more visible areas, such as the face, had a greater emotional impact than less visible areas. In particularly, fear of discrimination and rejection as a result of altered appearance were apparent: ‘…being treated with discrimination, being rejected, and sarcasm and spite were inevitable.’ (Hu et al., 2009,

p. 329). Moreover, less visible changes in the body envelope, such as male mastectomies, could also lead to embarrassment and fear of judgement: ‘I don’t think I’ll be stripping off this year… and if you wear a tight shirt you’re lopsided.’ (France et al., 2000, p. 345). In particular, breast cancer, which is more associated with women, was a source of stigma for men who had contracted this type of cancer. Men found conversations about their diagnosis and treatment with friends and family difficult, as it was often assumed that breast cancer was a ‘women’s problem’: ‘I could have talked to other people but they actually feel embarrassed because it is seen as a woman’s complaint, it’s daft for a bloke to have breast cancer’ (France et al., 2000, p. 345).

In contrast, men who experienced cancer associated with men, such as prostate cancer, found it easier to be open about their cancer and the side-effects of treatment: ‘Because I have told them all now, and [it’s easier to talk] when you know you don’t need to try to conceal something.’ (Oster et al., 2013, p. 335). The process of being open and honest about their cancer experience strengthened their existing relationships and helped form new friendships, leading to greater acceptance of their situation.

However, changes in the body envelope had the capability of effecting relationships, via diminished self-esteem and confidence, resulting in social withdrawal and isolation as a way of attempting to manage these difficult feelings. Moreover, a lack of social contact had the potential to lead to experiences of depression and anger, along with negative feelings directed towards themselves:

> I did not want to go out. I felt very depressed and angry with my altered appearance, because I was totally unprepared; it was painful for me to accept this. The reason I felt depressed was that I saw myself slobbering . . . everyday . . . and that has affected my self-esteem. (Hu et al., 2009, p. 329).

Similarly, changes to the body that impeded acts of partner intimacy as a result of surgery were sources of concern and distress for both men and women. Some men found that feeling sexually inadequate led to emotional changes ranging from angry to sad: ‘I have experienced that I have become so temperamental. My mood changes so quickly. I can lose my temper . . . inside myself . . . and then it can go the other way and I get sad’. (Oster et al., 2013, p. 335). In comparison, some women were concerned about their ability to remain sexually attractive to their partners as a result of a mastectomy: ‘When I look at myself in the mirror, I just want to cry. I feel it is not me. Where is the good looking woman whom I knew? How my spouse will even look at me now?’ (Joulaee et al., 2012, p. 3).

In contrast, women who undertook surgery to remove the invisible uterus, in essence castrating surgery, did not experience negative feelings about their bodies: ‘I am the same even if some parts of my body have been removed.’ (Ekman et al., 2004, p. 180). Furthermore, the emotional experience from undergoing a bone marrow transplant, after being diagnosed with haematological cancer, was notably different to that experienced by those whose treatment resulted in changes to the body envelope, suggesting that changes in body image had an emotional impact post-surgery.

Reflections on the emotional journey having completed treatment

The completion of cancer treatment gave pause for reflection on the impact of having cancer. Comparisons were commonly made between outlook of life and priorities pre and post cancer. Some of the changes were profound and reflected feelings of being grateful for being alive and healthy, savouring the moment and viewing the world with a sense of awe.

> My world has absolutely changed. I could hardly feel how valuable my health was, but now I want to devour any single moment of my life. Everything is important, even simple natural events such as rain, sunshine . . . in everyday life can be a message to help me discover the meaning of life. (Joulaee et al., 2012, p. 5).

Similarly, even when the cancer treatment journey had resulted in visible differences and stigma, acceptance and hope for the future were experienced: '. . . I am only 40. So I tell myself just face the music... I never think it is a burden; it is a part of my life now.' (Hu et al., 2009, p. 330).

However, despite successful completion of curative cancer treatment, many difficult emotions related to cancer remained for many people. Check-up protocols could be a source of uncertainty and reassurance for many, acting as a reminder of the potential of contracting cancer again, and providing confirmation that cancer had not returned. Furthermore, fear of cancer returning led to hypervigilance, checking the body for any changes that may signal the presence of cancer: 'It has almost become a routine now that when you have a shower you look at yourself and check that everything is ok.' (Vaartio et al., 2003, p. 185).

Moreover, despite having successful curative treatment, for some people aspects of the treatment itself were a greater source of fear than that of contracting cancer again:

> I worry about developing secondary forms of cancer and having to go through treatment again. Cancer itself does not scare me – it is the treatment that scares me…I would really like to forget about the cancer. I get so upset always thinking about being monitored all my life… that the cancer doesn't come back. (Leal et al., 2015, p. 142).

Therefore, cancer treatment of and in itself could elicit many distressing emotions above and beyond its contraction. Primarily there is a sense that cancer continues to pose a threat and that regular medical monitoring could act as a reminder of this threat, potentially eliciting feelings initially evoked during cancer treatment. However, having undertaken and completed successful curative treatment, many participants found a new sense of self, demonstrating personal growth as a result of completing the journey.

Discussion

This review has highlighted some key emotional experiences related to undertaking and completing a curative cancer journey. The emotional journey was analysed in four emotional sequential transition points: rapidly changing emotions at diagnosis; an action focused period with fewer and more stable emotions at the time of treatment; anger and sadness at what has been lost, post treatment; life after treatment signalled a period of emotional reconciliation and benefit finding. The thematic synthesis method has allowed for many different types of cancer and a varied sample to be incorporated into the review from which common emotional experiences and concerns have been identified. Due to the variation in the studies (country of origin and type of methodology) and sample characteristics (such as age, cancer stage, as well as gender and culture), the review findings can be considered theoretically generalizable (Yardley, 2000). Furthermore, demonstration of how emotional experiences are related to coping strategies, are important considerations for health care services and organisations involved in cancer treatment and recovery.

Other thematic syntheses have revealed similar temporally structured themes that denote different pockets of experience split by life pre, during and post diagnosis and treatment for chronic conditions, for example, a thematic synthesis on experiences of dementia (Bunn, et al., 2012). Furthermore, a thematic analysis on human immunodeficiency virus (HIV) (Heiland et al., 2008) split the analysis into five time periods from pre diagnosis through to the future with HIV, in order to illustrate how meaningful activities changed over time.

Being diagnosed with cancer, a potentially life threatening illness, associated with difficult and assumed maladaptive feelings, did not turn out to be a life shattering event. In fact, similar to other long term conditions such as dementia (see Bunn et al., 2012 for a review), many studies reported participants adopting new insights and life perspectives as a result of having cancer, despite initially experiencing difficult emotions related to cancer diagnosis and treatment.

Furthermore, participants illustrated how over time social comparisons were used in order to adapt. This was particularly striking post cancer treatment when hopes of returning to their ‘old lives’ held during treatment had given way to the realisation that life, as a result of experiencing cancer, would be different, despite no longer having a cancer diagnosis. This was particularly apparent when changes in the body envelope occurred as a result of cancer treatment. More specifically, people with more visible difference as a result of treatment, could experience feelings of embarrassment and shame that often led to social avoidance, for fear of judgement. In these circumstances, opportunities to self-regulate with others having undergone similar lived experience were particularly valued and beneficial. Similar themes have been demonstrated in other areas, such as amputee experiences (see Murray & Forshaw, 2013, for a metasynthesis) in which changes in identity occurred as a result of limb amputation and social comparisons were demonstrated as a useful mechanism for adopting and adapting to a new sense of self.

Gender differences in emotional responses were detected. As observed in studies of men with cancer in this review (Hu et al., 2009; Oster et al., 2013; Vaartio et al., 2003) men tended to talk about concrete actions as opposed to emotional experiences. Men tended to turn to female spouses or family members for emotional support and expression, whereas women were more likely to be more emotionally expressive about both their own and their spouses’ experiences. This phenomenon has been explained through socially constructed as well as cultural differences (Seymour-Smith & Wetherell, 2006). Furthermore, as noted by Hu et al. (2009), men are less likely acknowledge the need for and accept more formal types of support, instead preferring the more informal support from other men who have shared similar experiences. This is an important consideration for cancer services offering support, particularly when difficult feelings or embarrassment are being experienced as a result of cancer treatment.

Furthermore, partners and family members were often mentioned, by both men and women, as important sources of emotional support throughout their cancer treatment. Given the importance of partners and family members, their inclusion in psychoeducation and interventions around support could be an important addition, particularly in reducing feelings of isolation, which are often involved in the cancer journey.

Finally, having faced cancer treatment and the many emotional experiences expressed through the narratives of the participants involved, it is clear that distress, hope and expressions of personal growth are often intertwined, as opposed to discrete states. Therefore, this review supports studies that have demonstrated that the complex and evolving nature of felt emotions, where difficult emotions can co-exist with experiences of personal growth and contentment.

However, it should be noted that each participant used and had available to them different strategies and resources in order to cope with their cancer journey. Furthermore, despite some participants having had the same cancer type and undergoing similar treatment protocols, how each participant felt and reacted to their situation varied. Some mentioned having supportive spouses, family and friendships and using these relationships in order to navigate the many demands that undergoing cancer treatment brought. Other participants spoke about difficulties in their relationships and coping with responsibilities and stressors. Differences in both resources available to an individual and the amount of stressful factors they were attempting to balance is likely to mean that any interventions would need to be both flexible and timely enough to take into account each individual’s set of circumstances. This has implications for cancer services as being able to access them at the right time and receive a unique level of support, tailored to an individual will be important for delivering effective interventions.

In terms of limitations, the thematic synthesis relies on the language of the participants to illustrate their emotional experience. However, social and cultural norms exist that influence how emotions are expressed, for example, in the UK there was a culture of 'being positive' in cancer care. Although there is every reason to suspect that this culture was adopted more widely as one of its functions was negate fears of concerned friends and relatives (McCreaddie, Payne & Froggatt, 2010). However, this review also relied on the interpretations of the researchers, who would have had an awareness of social and cultural norms and interpret participants' quotes within this context. Furthermore, cultural differences in cancer treatment were detected in the process of conducting this review which were not explored, such as access to the healthcare and type of health care provided. However, this could prove a valuable line of enquiry for future research.

In conclusion, this review has provided a thematic synthesis of 12 papers in order to identify and understand the important emotional experiences of people undergoing cancer treatment. This review used key stages of the cancer journey in which emotional experiences intensify and highlights how these emotions interplay with thoughts and actions designed to manage and cope with changing life and identity resulting from a diagnosis of cancer and its subsequent treatment. The synthesis demonstrates and consequently supports the view that emotions throughout the cancer journey are complex and numerous. Furthermore, these emotional experiences often lead to the natural adaption and adoption of a new perspectives and identities that differ from those held before cancer. However, it should be noted that there are points in the cancer journey that can be experienced as particularly difficult, which may prove more so for individuals who are less resourced to cope with these experiences, due to social isolation or cancer type and treatment, who may require more support and intervention.

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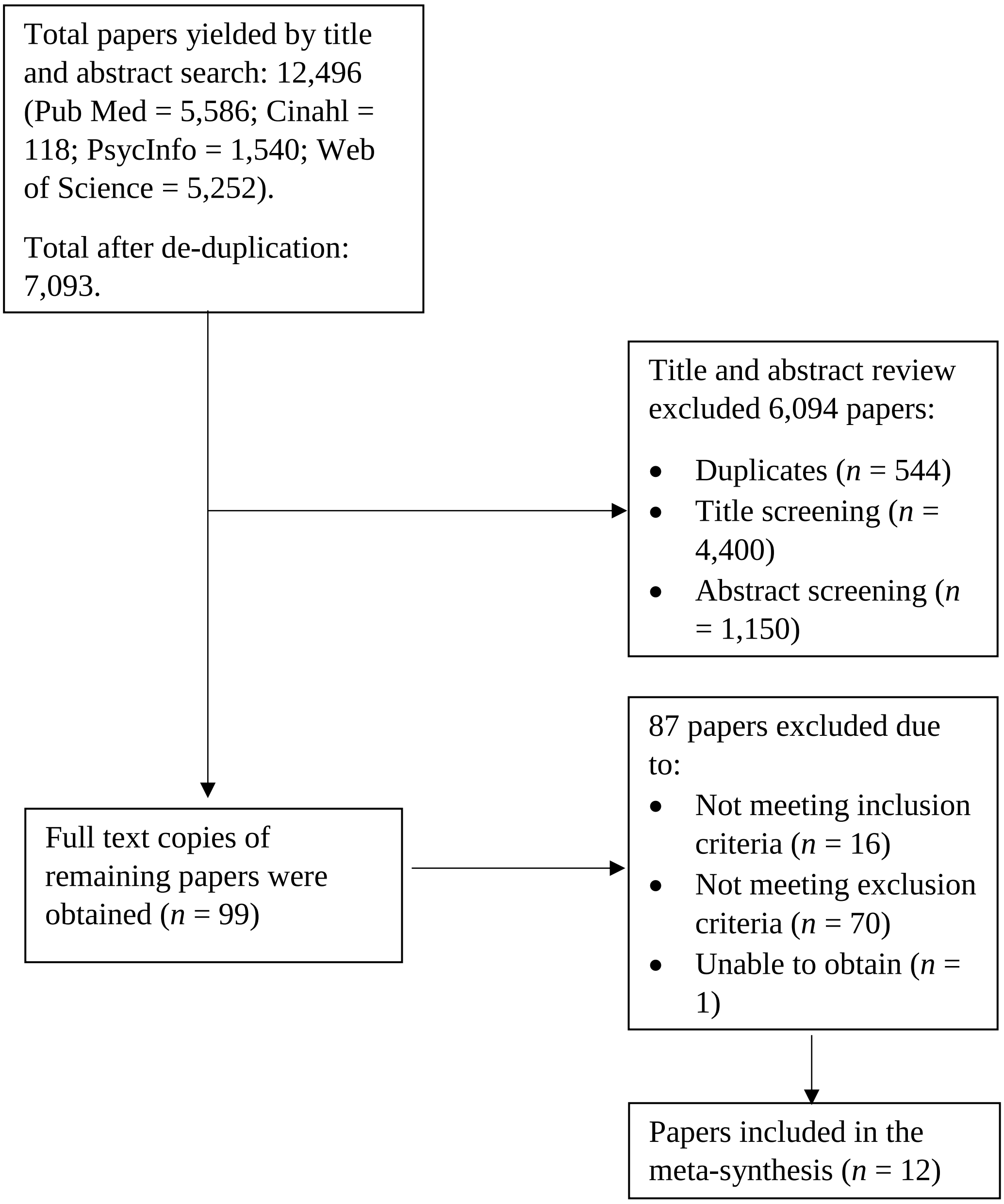

Figure 1. Flow diagram for inclusion of papers in the thematic synthesis.

Table I. Summary information of the papers selected for the meta-synthesis.

Study No.	Authors	Research question/aim	Methodology	Participants
1	Ekman et al., 2004	Enrich the understanding of the patient's perspective of being diagnosed and treated for ovarian cancer.	Hermeneutical approach Interviews conducted on 3 occasions (diagnosed, during treatment, completion of treatment) (n-23).	Sample size = *n* - 10. Aged: 21 -56. Sex: Female.
2	France et al., 2000	Describe psychological and social consequences of breast cancer in men.	Phenomenological approach Unstructured interviews conducted in participants home with spouse invited to participate if present.	Sample size = *n* - 6. Aged: known. Sex: Male. Completed curative treatment.
3	Hu et al., 2009	Provide in-depth depictions of the experience or oral cancer in Taiwanese men.	Thematic analysis Semi- structured interviews conducted face to face in hospital room or at home.	Sample size = *n* - 6. Aged: 40 -57. Sex: Men. Completed curative treatment for non-terminal cancer.
4	Joulaee, et al., 2012	Explore the meaning of living with cancer for Iranian women.	Phenomenological approach Semi- structured interviews conducted in a private breast cancer clinic.	Sample size = *n* - 13. Aged: 34 -67. Sex: Women. Completed curative treatment, including mastectomy/lumpectomy and chemotherapy/ radiotherapy.
5	Leal et al., 2015	Explore patients' experiences of cancer over time. (Part of an RCT for a yoga intervention).	Content analysis using a framework approach Semi-structured written narratives, recorded at one week and three months post a yoga intervention.	Sample size = *n* - 28. Aged: 34 -67. Sex: 18 Women, 10 men. Diagnosed with lymphoma who are receiving curative treatment or had received treatment in the last 12 months.

Table I. (Continued)

Study No.	Authors	Research question/aim	Methodology	Participants
6	Oster et al., 2013	Describe experiences of men living with prostate cancer.	Content analysis Focus group with men undergoing a course of curative radiotherapy treatment.	Sample size = *n* - 9. Aged: 26 - 58. Sex: men. One of two groups (split *n* - 6 & *n* - 3) that met six or seven times.
7	Papadopoulou, et al., 2016	Explore patients' main pathways toward making sense of have been diagnosed with acute leukaemia within the first year after diagnosis or relapse.	Interpretative phenomenological analysis approach Two Face to face semi- structured interviews at two to four week intervals.	Sample size = *n* - 10. Aged: 18 – over 61. Sex: Women = *n* - 3, Men = *n* - 7. 20 interviews in total
8	Taleghani, et al., 2008	To investigate the experience from the patients perspective and how they interact with others and interpret their experiences in adjusting to the disease.	Grounded theory 2 Hospitals in Tehran (a university hospital and a private hospital).	Sample size = *n* - 20 during treatment and 15 after treatment. Aged: 31 -56. Sex: Women = 45 interviews in total.
9	Vaartio, et al., 2003	Find out what male cancer patients regarded as most problematic during their illness trajectory, what kind of internal and external resources they use and how they experienced social support during the illness trajectory.	Content analysis Semi- structured interviews conducted in a private breast cancer clinic.	Sample size = *n* - 8. Aged: 42 - 64. Sex: men. Diagnosed with melanoma, stomach cancer, lung cancer, Hodgkin's disease, testicular cancer, prostate cancer and bladder cancer.

Table 1. (Continued)

Study No.	Authors	Research question/aim	Methodology	Participants
10	White-Means, et al., 2015	Explores experiences during and post treatment that contributed to their beating the high odds of mortality.	Thematic analysis Focus group using semi-structured interview.	Sample size = *n* - 10. Aged: 38 - 62. Sex: women. Diagnosed with breast cancer.
11	Winterbottom & Harcourt, 2004	Experience of living through a skin cancer diagnosis. (Only malignant melanoma sample used)	Thematic content analysis 1:1 semi-structured interviews.	Sample size = *n* - 5. Aged: 24 -90. Sex: 3 women & 2 men. Diagnosed with malignant melanoma skin cancer.
12	Xuereb & Dunlop, 2003	Experience of haematological cancer through leukaemia or lymphoma and a bone marrow transplant.	Phenomenological analysis Face to face semi-structured interviews. Haematology units of three major hospitals in Sydney	Sample size = *n* - 10. Aged: 27 - 54. Sex: 6 women & 4 men. .

Table II. Critical appraisal of study quality using the CASP qualitative appraisal tool.

Study	Authors	*Research design	Sampling	Data collection	Reflexivity	Ethical issues	Data analysis	Findings	Value of research	Total score
1	Ekman et al., 2004	3	3	2	3	2	3	3	2	21
2	France et al., 2000	3	3	3	1	1	2	3	2	18
3	Hu et al., 2009	2	2	3	1	2	2	3	2	17
4	Joulaee et al, 2012	2	2	2	1	2	2	3	2	16
5	Leal et al., 2015	3	2	3	1	1	3	3	3	19
6	Oster et al., 2013	2	2	3	1	2	2	3	2	17
7	Papadopoulou et al., 2016	3	3	3	3	3	3	3	3	24
8	Taleghani et al., 2008	3	3	3	1	2	2	3	2	19
9	Vaartio, et al., 2003	2	2	2	1	2	2	3	2	16
10	White-Means et al, 2015	2	3	3	1	2	3	3	3	20
11	Winterbottom & Harcourt, 2004	2	3	3	1	3	2	2	2	18
12	Xuereb & Dunlop, 2003	3	3	3	1	2	2	2	3	19

* Items in columns 2-9 here correspond in the same order to items 3-10 on the CASP appraisal tool.

Table III. Study contribution to reviewers' themes.

Study	Authors	Reviewers' themes contributed to
1	Ekman et al., 2004	Being diagnosed and facing treatment Getting rid of cancer Changed body and stigma
2	France et al., 2000	Being diagnosed and facing treatment Getting rid of cancer Changed body and stigma
3	Hu et al., 2009	Being diagnosed and facing treatment Changed body and stigma Reflections on the emotional journey having completed treatment Reflections on the emotional journey having completed treatment
4	Joulaee, et al., 2012	Being diagnosed and facing treatment Changed body and stigma Reflections on the emotional journey having completed treatment
5	Leal et al., 2015	Being diagnosed and facing treatment Getting rid of cancer Reflections on the emotional journey having completed treatment
6	Oster et al., 2013	Being diagnosed and facing treatment Getting rid of cancer Changed body and stigma Reflections on the emotional journey having completed treatment
7	Papadopoulou, et al., 2016	Being diagnosed and facing treatment Getting rid of cancer Reflections on the emotional journey having completed treatment
8	Taleghani, et al., 2008	Being diagnosed and facing treatment Getting rid of cancer Changed body and stigma Reflections on the emotional journey having completed treatment
9	Vaartio, et al., 2003	Being diagnosed and facing treatment Getting rid of cancer Changed body and stigma Reflections on the emotional journey having completed treatment
10	White-Means, et al., 2015	Being diagnosed and facing treatment Getting rid of cancer Changed body and stigma Reflections on the emotional journey having completed treatment
11	Winterbottom & Harcourt, 2004	Being diagnosed and facing treatment Getting rid of cancer
12	Xuereb & Dunlop, 2003	Being diagnosed and facing treatment Getting rid of cancer

Appendices

Appendix A

Exact terms input for each database search

PUB MED

(((((cancer patient*[Title/Abstract]) OR (patient*[Title/Abstract... (5586)

(((((cancer patient*[Title/Abstract]) OR (patient*[Title/Abstract] OR client*[Title/Abstract] OR individual*[Title/Abstract]))) AND ((‘Neoplasms’[Mesh]) OR cancer*[Title/Abstract])) AND (emotion* OR experience* OR perception*)) AND ((‘interviews as topic’[Mesh:noexp] OR ‘focus groups’[Mesh:noexp] OR narration[Mesh:noexp] OR qualitative research[Mesh:noexp] OR (((‘semi-structured’[TIAB] OR semistructured[TIAB] OR unstructured[TIAB] OR structured[TIAB] OR informal[TIAB] OR ‘in-depth’[TIAB] OR indepth[TIAB] OR ‘face-to-face’[TIAB] OR guide[TIAB] OR guides[TIAB]) AND (interview*[TIAB] OR discussion*[TIAB] OR questionnaire*[TIAB])) OR (‘focus group’[TIAB] OR ‘focus groups’[TIAB] OR qualitative[TIAB] OR ethnograph*[TIAB] OR fieldwork[TIAB] OR ‘field work’[TIAB] OR ‘key informant’[TIAB]))))

CINAHL

S1 AB neoplasms or oncology or cancer Search modes - Find all my search terms
S4 emotion* OR experience* OR perception* Search modes - Find all my search terms
S6 S2 OR S5
S5 - AB individual* OR client* OR patient*
S2 – AB ‘cancer patients’
Limiters - Exclude MEDLINE records; Human; Clinical Queries: Qualitative - High Specificity; Age Groups: All Adult

PsychInfo

S9

S5 AND S6 AND S7

Limiters - Publication Type: Peer Reviewed Journal; English; Age Groups: Adulthood (18 yrs & older); Population Group: Human; Methodology: QUALITATIVE STUDY; Exclude Dissertations

Search modes - Find all my search terms

View Results (1,540) View Details Edit

Appendix A contd.

S8
S5 AND S6 AND S7
Search modes - Find all my search terms
View Results (10,273) View Details Edit
S7
S3 OR S4
Search modes - Find all my search terms
View Results (1,121,860) View Details Edit
S6
S1 OR S2
Search modes - Find all my search terms
View Results (55,776) View Details Edit
S5
AB emotion* OR perception* OR experience*
Search modes - Find all my search terms
View Results (825,019) View Details Edit
Appendix A contd.
S4
AB patient* OR client* OR individual*
Search modes - Find all my search terms
View Results (1,121,860) View Details Edit
S3
AB cancer patients
Search modes - Find all my search terms
View Results (24,247) View Details Edit
S2
AB cancer
Search modes - Find all my search terms
View Results (47,474) View Details Edit
S1
DE ‘Neoplasms’ OR DE ‘Benign Neoplasms’ OR DE ‘Breast Neoplasms’ OR DE ‘Endocrine Neoplasms’ OR DE ‘Leukemias’ OR DE ‘Melanoma’ OR DE ‘Metastasis’ OR DE ‘Nervous System Neoplasms’ OR DE ‘Terminal Cancer’

Limiters - Publication Type: Peer Reviewed Journal; English; Age Groups: Adulthood (18 yrs & older); Population Group: Human; Methodology: QUALITATIVE STUDY; Exclude Dissertations

Appendix A contd.

WEBOfScience

# 9	**5,252**	#8 AND #5 AND #4 AND #3 Indexes=SCI-EXPANDED, SSCI Timespan=All years	Edit Select to combine sets. ☐	Select to delete this set. ☐
# 8	**381,438**	#7 AND #6 Indexes=SCI-EXPANDED, SSCI Timespan=All years	Edit Select to combine sets. ☐	Select to delete this set. ☐
# 7	**1,439,812**	**TOPIC:** (interview OR discussion OR questionnaire* OR focus groups* OR qualitative OR ethnograph* OR fieldwork OR field work OR key informant) Indexes=SCI-EXPANDED, SSCI Timespan=All years	Edit Select to combine sets. ☐	Select to delete this set. ☐
# 6	**4,444,725**	**TOPIC:** (interviews as topic OR focus groups OR narration OR qualitative research OR semi-structured OR semistructured OR unstructured OR structured OR informal OR in-depth OR indepth OR face-to-face OR guide OR guides) Indexes=SCI-EXPANDED, SSCI Timespan=All years	Edit Select to combine sets. ☐	Select to delete this set. ☐
# 5	**1,897,676**	**TOPIC:** (cancer* OR neoplasm*) Indexes=SCI-EXPANDED, SSCI, A&HCI, CPCI-S, CPCI-SSH, ESCI Timespan=All years	Edit Select to combine sets. ☐	Select to delete this set. ☐
# 4	**2,096,253**	**TOPIC:** (experience* OR perception* OR perspective*) Indexes=SCI-EXPANDED, SSCI, A&HCI, CPCI-S, CPCI-SSH, ESCI Timespan=All years	Edit Select to combine sets. ☐	Select to delete this set. ☐
# 3	**4,546,508**	#2 OR #1 Indexes=SCI-EXPANDED, SSCI, A&HCI, CPCI-S, CPCI-SSH, ESCI Timespan=All years	Edit Select to combine sets. ☐	Select to delete this set. ☐
# 2	**4,546,508**	**TOPIC:** (patients* OR clients* OR individuals*) Indexes=SCI-EXPANDED, SSCI, A&HCI, CPCI-S, CPCI-SSH, ESCI Timespan=All years	Edit Select to combine sets. ☐	Select to delete this set. ☐

Appendix A contd.

# 1	**157,090**	**TOPIC:** (‘cancer patients’) Indexes=SCI-EXPANDED, SSCI, A&HCI, CPCI-S, CPCI-SSH, ESCI Timespan=All years	Edit	Select to combine sets.

Appendix B

Example page of a data extraction table

Paper	Research question/aim	Methodology	Participants
Ekman et al. (2004)	Enrich the understanding of the patient's perspective of being diagnosed and treated for ovarian cancer.	Hermeneutical Approach Interviews conducted on 3 occasions (diagnosed, during treatment, completion of treatment) (n-23).	Sample size = n-10. Aged: 21 -56. Sex: Female.

Results

Reactions to Diagnosis of cancer: 2 main types: little surprise or difficultly in grasping the fact. The difference in reaction seemed to be connected with perceptions of cancer (i.e. causes death or a treatable tumour). So it was not a big surprise. In some strange way I knew what it was. But the thing that astonished me was that I never felt tired or depressed. Connected bodily signs to cancer 'hard belly' or urinary incontinence. Feeling of a 'spider in the body'.
Versus those whom associated cancer with death or had experience with others who had died from cancer. At the time felt 'strong' or 'should make it' The future is not accessible and I have no plans anymore.

Described the mixed feelings that changed rapidly fear, strength, willingness to fight, astonishment, sadness, disappointment, shock, hope, worry, chaos and emptiness. Everything was chaotic, and I didn't have one clear thought in my head'.

Patient's Thoughts and Feelings During Chemotherapy: Cancer became real and close. Bodily signs such as alopecia developed. 'Fear' of cancer developing in other part of the body but strong feelings of 'hope' that they would be cured. Treatment connected to feelings of hope 'It must be something very strong in the medicines in that you feel so sick, but it will surely take away the cancer cells.'
Cancer is something 'evil' that should be removed from the body.

Taking blood samples mentally difficult as it was a reminder of having a disease.

Treatment even if good lead to problems (nausea, vomiting, fatigue, sweating, stress, loss of hair, isolation, stomach pain, heartburn, and anxiety).

Feeling of have a 'big gash' after Chemo that should be healed – confirmation that treatment was effective.

Feeling the Same Despite Castrating Surgery: Despite removal of organs women did not feel differently about their bodies. 'I feel exactly the same.' ' I am the same even if some parts of my body have been removed.'

Acceptance of Chemotherapy: 'The chemotherapy is a good poison that I believe in'. The chemo was referred to in terms of something that would 'cleanse' the body of toxins.

Appendix C

Example of a grouped concept

3	4	5	7	8	9	10
Hu et al 2009	Joulaee at al 2012	Leal et al 2015	Papadopoulou et al. 2016	Taleghani et al. 2008	Vaartio et al. (2003)	White-Means et al. (2016)
Oral Cancer	Breast Cancer	Lymphoma	Leukemia	Breast Cancer	Mixed Cancer (males)	Breast Cancer
Adapting to difference: Participants used a variety of strategies to adjust to their new appearance and the reality of living with cancer. These included trying to maintain a positive attitude; developing self-reliance; accepting their appearance; modifying their lifestyle; setting new life goals; and seeking knowledge about healthy living. Three have become cancer volunteers at the hospital where they were treated.	Positive aspects: This was shown with explaining how a new look at the life could provide the women with breast cancer a wider angle of the human life.	Experience of paradox: coexistence—contradictory and surreal	Transformation and Growth: Assimilating Leukemia: The assimilation of leukemia starts within the transformation process and develops toward growth via the realization of mortality and the reprioritization of personal values. Leukemia, like any life-threatening illness, shakes two common assumptions: those of immortality and invincibility. Described how he felt as 'unnerving' choosing not to think about death. Another participant explained that 'brushed with death' have made her reprioritise was important in her life.	Living with the Disease with Tolerance After all the treatments the fear that cancer might return kept them from future adjustment.	As soon as they had any pain or discomfort they suspected a relapse or metasasis: 'It has almost become a routine now that when you have a shower you look at yourself and check that everything is ok.'	Every survivor agreed that their lives had changed forever, due to breast cancer. They now appreciate life a whole lot more.

Appendix D

Psychology & Health – Guidelines for Author

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Contents

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5. Funding details. Please supply all details required by your funding and grant-awarding bodies as follows:
   For single agency grants
   This work was supported by the [Funding Agency] under Grant [number xxxx].
   For multiple agency grants
   This work was supported by the [Funding Agency #1] under Grant [number xxxx]; [Funding Agency #2] under Grant [number xxxx]; and [Funding Agency #3] under Grant [number xxxx].
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Updated 2-11-2017

Thesis Section 2: Empirical Paper

The narratives of difficult emotional experiences throughout the cancer treatment journey.

Intended journal - Psychology & Health

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Doctorate in Clinical Psychology

Lancaster University

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Abstract

Aim**:** To illustrate the self-directed difficult emotional narratives of people who had been treated for cancer.

Method**:** Six adults, treated for different cancer types, were recruited from different cancer charities in the north-west of England. A narrative approach was used to extract acts of self-directed difficult emotions from across the stories.

Findings: Four themes or acts that contained difficult emotions directed at the self emerged and included demonstrations of how and when disgust, guilt, shame and fear were experienced and as the narratives unfolded, how and when these emotional experience changed the self.

Discussion: The findings are partly consistent with previous research. However, there are indictors that the self-directed disgust schema may be initiated as a result of physical changes associated with cancer treatment.

Keywords: Cancer, Emotions, Disgust, Narrative-Analysis

Cancer, as with other long-term health conditions, can impact both an individual's mental health and how these individuals decide on and respond to treatment (e.g., DiMatteo, Lepper, & Croghan, 2000), adhere to treatment protocols (e.g., Reynolds, Bissett, Porter, & Consedine, 2016), and their duration of survival (e.g., Falagas et al., 2007). In particular, anxiety and depression have been argued to be important psychological experiences among people who have a cancer diagnosis and are undergoing treatment (Hinz et al., 2010).

However, having a diagnosis of cancer and subsequent treatment can involve experiencing a number of difficult emotions beyond the mental health problems of anxiety and depression, such as embarrassment, guilt and shame. Although difficult emotions cannot always be assumed to be maladaptive, emotional experience can influence psychological health and affect behaviour which can then have implications for interaction and engagement with treatment processes throughout the cancer treatment journey. For example, embarrassment and fear have been associated with delays in seeking medical care in cancer (e.g. Smith, Pope, & Botha, 2005). Feelings of self-blame, guilt and shame have been demonstrated in breast (e.g. Glinder & Compas, 1999), lung (e.g. Chapple, Ziebland, & McPherson, 2004; Coughlan, 2004; Gulyn & Youssef, 2010) and colorectal cancer (e.g. Phelan et al., 2013), which can lead to social avoidance and affect intimate relationships.

As well as shame, blame and guilt, more recently researchers have begun to consider the role of other emotions directed towards the self, such as self-disgust. Self-disgust as a psychological concept is relatively new, although features unique to disgust can be used to distinguish self-disgust from other closely-related affective phenomena (i.e., shame, self-hatred) in the general population. Theoretically, self-disgust can be viewed as an emotional schema by which disgust is directed towards the self and, if enduring, can have negative consequences for a range of mental health and behavioural outcomes (Powell, Simpson, &

Overton, 2014a). Schemas can be defined as cognitive frameworks that organise and interpret pieces of information and the relationships among them (DiMaggio, 1997). Similarly, emotional schemas are patterns of associations between perception, emotion, appraisals and cognition (Izzard, 2007)

Much of the research on self-disgust to date is concentrated in mental health. For example, self-disgust has been shown to function as an antecedent to the depressive experience and play a role in depression (Overton, Markland, Taggart, Bagshaw, & Simpson, 2008). However, certainly from a theoretical perspective, self-disgust may also persist in the absence of depressive experience (Powell et al., 2014a), and there is some support for this in a recent longitudinal study (Powell, Simpson & Overton, 2013). The same research also found that disgust towards physical aspects of the self may be a more important predictor of depressive experience over time than disgust towards behavioural aspects of the self (Powell et al., 2013). It is likely that physical aspects of oneself that initiate self-disgust may also be especially important in physical health conditions such as cancer (Reynolds, McCambridge, & Consedine, 2015). Furthermore, physical symptoms of ill health, as well as the effects of treatment, have the potential to initiate the self-disgust schema; therefore, in long-term physical health conditions these self-disgust elicitors can become commonplace and unavoidable (Reynolds et al., 2015).

Due to the infancy of the concept of self-disgust, few studies have explored the role of disgust directed at oneself in people with long-term physical health conditions. Recent studies using quantitative methodology have found that self-disgust is a mediator of psychological distress in adults with cancer (Azlan, Overton, Simpson, & Powell, 2016; Powell, Azlan, Simpson, & Overton, 2016). The former study found that disgust sensitivity was more likely to predict depressive symptoms in cancer populations than matched controls (Azlan et al., 2016). The latter study found that experiencing physical side-effects of cancer treatments, such as nausea and bowel and bladder problems, considered to be elicitors of core disgust responses, were indicative of increased psychological distress. Furthermore, the effect of core disgust side-effects on self-disgust were also moderated by one's underlying disgust propensity. In addition, self-directed disgust mediated the impact of core disgust side-effects on psychological adjustment to cancer treatment (Powell et al., 2016), highlighting the relevance of self-disgust in relation to the cancer journey.

Additional indicators suggest that disgust is of particular importance in cancer treatment. For example, a secondary analysis of a randomised control trial of 68 cancer patients assigned to a mindfulness or relaxation intervention investigated the impact of emotions on different types of avoidance such as cognitive, social, and treatment avoidance in people undergoing chemotherapy. Compared with other difficult emotions (i.e., embarrassment and distress), disgust propensity was the most consistent predictor of cognitive, social, and emotional avoidance (Reynolds et al., 2016). This finding gives further weight to the importance of difficult emotions, particularly the role of disgust in cancer treatment.

However, the theoretical story of how self-directed emotions, including self-disgust, develop and change throughout the course of cancer treatment is as yet unexplored. Due to the schematic appraisal driven by self-disgust, it is likely that the disgust-based rejection of others may also be anticipated, leading to social withdrawal in order to avoid the expected rejection from others. Therefore, it is suspected that self-disgust may be an important mechanism underpinning the social withdrawal common in adaption to long-term physical health conditions, including cancer (Reynolds et al., 2015). In contrast, although current theories of self-disgust highlight negative implications, such as avoidance, self-disgust as a potential protective mechanism is even less well understood in a physical health context. Moreover, given the original role of disgust in the protection from threats to health, physical health maybe a context in which self-disgust may also be beneficial, for example, avoiding social contact during chemotherapy reduces the risk of infection. Given the role of self-disgust in avoidance and/or protection, its potential impact on interactions with treatment and psychological wellbeing and therefore recovery are important to consider.

Other concepts, such as stigma, have been implicated in social withdrawal as a result of having a cancer diagnosis (Chapple et al., 2004; Else-Quest, LoConte, Schiller, & Hyde, 2009; Lebel et al., 2013). Stigma results from undesirable external societal labelling of individuals and has been theorised to occur in two forms ‘felt’ and ‘enacted’. The felt form of stigma can be defined as an internalised sense of shame, as a result of an appraisal of oneself, from having a socially unacceptable condition and the anxiety of potential discrimination as a result. When discrimination occurs, this is enacted stigma (Goffman, 2009). However, stigma has been conceptualised more widely to include public and self – stigma that involves negatives beliefs, feelings and behaviours, for example awkwardness and avoidance of people with stigmatised illnesses (see Corrigan & Watson, 2002, for a review). A number of studies involving people with cancer (Else-Quest et al., 2009; Lebel et al., 2013) have found associations between perceived (felt) stigma and self-blame and poorer subsequent psychological adjustment. Additionally, disgust sensitivity of partners, as well as self-directed disgust in people with cancer, have been shown to lead to poorer psychological wellbeing (Azlan, Overton, Simpson, & Powell, in press). This suggests that psychological adjustment is affected by the difficult emotional experiences associated with these concepts. Furthermore, Lebel et al. (2013) found that stigma was reported more in people who had been visibly changed as a result of their cancer treatment.

Consequently, the primary aim of this study was to investigate the experience of difficult emotions directed at the self, throughout the course of cancer treatment. The evidence from personal narratives can highlight when these emotions are most prominent within the cancer treatment journey and, equally importantly, when and how they become more dormant, which can elucidate more theoretical questions, beyond reflections at specific points. Moreover, a greater understanding of the psychological trajectory of difficult emotions directed towards the self in people who have had cancer will provide guidance to health care professionals working with this population.

The specific research question for this study is: what are the narratives of self-directed difficult emotions in individuals who have experienced treatment for cancer, and how do these change perceptions of the self?

Method

Design

The aim of the study was to explore how the self is changed over the cancer journey and which difficult self-conscious emotions are associated with this. In order to achieve this aim a narrative analysis approach was adopted. In particular, the role of self-disgust and difficult emotions in avoidance and the potential impact on interactions with treatment, psychological wellbeing and recovery are of interest.

Procedure

The researcher liaised with a number of experts by experience from cancer organisations and the Lancaster University School of Health and Medicine Research Ethics Committee in order to ascertain acceptability of the study materials. Ethical approval was sought and gained from the aforementioned committee, prior to recruitment taking place.

Cancer charities within the North West of England were contacted and informed about the study. Charities willing to advertise the study were sent study advertisement materials along with the participant information sheet (see appendix D for participant information sheet). Any other information they wished to review, such as ethical approval, before promoting the study, was sent via university email. The promotion of the study by consenting organisations was done via electronic media channels such as social media, website, email and online forums, as well as more traditional routes such as newsletters, word of mouth and notice boards. Potential participants contacted the researcher directly or their contact details were sent via the charity organisation (after potential participants gave their permission for this information to be made available). The researcher contacted all potential participants and ensured that participants had received and read the participant information sheet and had had a chance to have questions answered before interview arrangements were made. If agreeable with the participant, a time and place for an interview to take place was made.

All interviews took place either within the centre in which the support groups were held or within participants' homes, dependent on the preference of the interviewee. Prior to the interview taking place, all participants were informed that that they could stop the interview at any time.

Given the nature of narrative analysis, in that it is interested in individuals' personal perspectives of their own story and sense of self by allowing space for the narrative to evolve, the interview was mainly unstructured and began by asking the main question: an invitation for participants to talk about their experience of difficult self-conscious emotions throughout their cancer journey. However, in order to maintain the focus of the research question, the researcher asked questions to clarify a point, or to expand on an area of interest, from a neutral position.

The duration of the interviews was between 31 and 95 minutes *(M = 68* minutes, *SD = 24* minutes). Participants were made aware that they were free to withdraw at any time up until the analysis and write up of the study without giving reason or experiencing negative consequences.

As current research suggests that people who have cancer show high prevalence rates of psychological distress (e.g. Zabora, BrintzenhofeSzoc, Curbow, Hooker, & Piantadosi, 2001), it was possible that sharing the story of their journey through cancer treatment had the potential to cause distress. Before the start of the interview, interviewees were asked about their preference of action, should they become upset. This included having a break, rescheduling, or contacting a named individual for support. In accordance with ethical approval, participants were given the option of choosing a pseudonym, having a pseudonym assigned by the researcher, or retaining their own name which can prevent ‘loss of ownership’ (Grinyer, 2002). All participants used either their name or derivative of their name. Consent to participate was gained via the completion and signing of a study consent form. Participants were signposted to services, if appropriate, and contact details made available as part of the study debrief. A summary of the findings was sent to consenting participants, once the study had been submitted for assessment.

Participants

All participants attended support groups run by regional cancer charities. They identified as having experienced difficult emotions about themselves, such as guilt, shame and disgust, from the definition given in the study information (see appendix C for study advertisement), either during or after their cancer treatment experience and prior to being interviewed. Participants interested in taking part in the study contacted the researcher to arrange an interview time and date.

Participants were 18 years and above at the time of interview, although may have been younger at the time of treatment. They could not have a ‘watch and wait’ tumour diagnosis or be in active treatment (i.e. radiotherapy/chemotherapy) when they were interviewed but could be on less invasive treatments (e.g., hormone therapy with tamoxifen). Participants needed to speak English, as it was preferred that the speaker and interviewer/researcher be fluent in the same language in order for robust interpretations to be made from the narratives (Temple & Young, 2004). Information on participant demographics was collected from the participants at the beginning of the interview and included age, gender, ethnicity, primary cancer diagnosis, type and duration of cancer treatment, age of onset and time elapsed since active treatment. Details of participants' demographics are displayed in Table 1.

[INSERT TABLE 1 HERE]

Sample

An open approach to the sampling was adopted. Six participants (four women and two men) aged between 57 and 77 years took part in the study. All participants categorised themselves as either White English or White British. The size of the sample reflected the idiographic approach taken, where the depth and richness of the analysis was privileged in order to gain theoretical generalisability (Morse, 2000). The types of primary cancer diagnosis included cancer of the breast, voice box, cervix and prostate, as well as lymphoma. The types of cancer treatment included surgical removal of the cancer in all cases, followed by a course of adjuvant therapy (chemo or radio therapy) for five participants (Dave, Joan, Marianne, Jules, Hazel). One participant had received two cancer diagnoses as well as a secondary cancer diagnosis (Joan). The time elapsed since being in active treatment ranged from 10 months to 12 years.

Analysis

Narrative analysis was used to analyse the interview data. This type of analysis places emphasis on the interplay between self and context. The core element of this type of analysis is the uncovering of the self-construct, in particular how participants viewed themselves and how this view is shaped. Furthermore, it is focused on the process of shaping of the self and the contributing factors involved (Weatherhead, 2011). This was a useful approach for answering the research question, in that it allowed for in-depth exploration of the development of difficult emotions directed towards the self, throughout cancer treatment.

All the interviews were undertaken and transcribed verbatim by the researcher (see appendix A for sample transcription). The narratives were read and re-read for key experiences that related to difficult emotions directed towards the self. An inductive process followed in which these experiences were compared and contrasted across the narratives and from which four temporal themes or Acts emerged (see appendix B for grouped data by Act). In addition, narratives were reviewed for cases which contradicted Act descriptions. The Acts, when considered appropriate, were modified to accommodate such divergence.

The type of analytical framework utilised was informed by Riessman (2005) and Williams (1984). These frameworks have a particular emphasis on ‘what’ is being said, within the content of narratives, in contrast to ‘how’ it is being said. As such, the narrative framework adopted was informed epistemologically by a critical realist position, whereby language is seen as a route to truth and meaning.

Qualitative approaches, including narrative analysis, assume that the researcher will to varying extents, influence the research findings. In order to ensure quality Yardley’s (2000) framework was adopted. In concordance with this framework the findings and interpretations were discussed with academic and field supervisors, in order that the most credible analysis be presented from the data. Furthermore, the use of participants’ language to illustrate and support findings enhanced the integrity of the analysis (Riessman, 2005: Yardley, 2000). Through reflection and supervision, the researcher’s own reflexive position and the potential influence of this on the analysis was limited. Finally, transcripts were searched for contradictory instances and themes adjusted to accommodate any disconfirming cases.

Findings

Four Acts were revealed from the analysis, which were ordered temporally. The Acts reflect common emotional experiences of the participants interviewed. However, each narrative is not necessarily represented in every Act, rather the potency of the emotional experience by the majority. When reading the quotations, […] indicates omitted words.

Act 1 – ‘I want it out’

The emotion of disgust entered the narratives at different time points. However, there was much overlap between participants experience of disgust entering the narratives during the process of attempting to eliminate cancer from the body throughout treatment. This act encapsulated the feeling of a need to cleanse the body of the contamination of cancer.

Hazel’s narrative highlighted the priority given to ridding the body of this contaminant. Other treatment options that may have meant prolonging cancers occupation within the body were discounted, despite the consequences of its immediate removal, being the loss of her voice: ‘I wanted it out. Get it out, out of the way. I had no alternative’. The primary behavioural tendency associated with disgust is rejection (Rozin, Haidt, & McCauley, 2000). The above scene illustrated that the thought of cancer remaining in the body was so disgusting that it was immediately rejected: ‘I wanted it out’, eluded to the intensity of the desire to rid the self of this undesirable and contaminated property.

Hazel’s narrative goes on to talk about her stay in hospital:

> I just wanted get home from the hospital, back to living in my own house. I just wanted the hospital stay and all that goes with being in hospital, the…alien environment, as you might call it, to be over and done with. I mean being in hospital a couple weeks... which wasn't that long really, is an environment in which you become quite institutionalised, I feel. You rely on staff. I mean I had to learn how put a tube in there [points to throat] and clean it and make sure I didn't get blocked up with mucus. Now that's fine they are showing you how to cope with life, but the quicker you do it, the quicker you get home. But after two weeks in you feel rather cocooned, being looked after.

Hazel’s use of the word ‘alien’ in reference to the hospital environment is interesting and suggests that this may act as a disgust elicitor and therefore, create a need to gain distance from it. The idea of disgust objects being ‘matter out of place’ has been proposed in relation to that which has an ‘alien’ characteristic about it (Douglas, 2003). Furthermore, the hospital environment may have signified the disgusting features of the unhealthy self, for example, ‘being blocked up with mucus’, creating a desire to protect the healthy self, by rejecting reminders of the sick self, including ‘being looked after’.

Other elicitors of disgust entered the narratives during active treatment. Treatment itself could elicit a disgust response. Marianne’s narrative highlighted how she felt about having radiotherapy:

> Very daunting at first, you know, because you just don't know what's going to happen... But after the first couple, it was alright really, I got on with it. It made me feel tired. Erm, I didn't like [pauses]. You have to sit there with your arms in a clamp and sit very still and I didn't like that, so. I just had weird thoughts about it, thinking 'Oh, is it doing me good or not'.

Clearly, fear is an emotion within the narrative, however, Marianne’s appraisal of the radiotherapy treatment ‘is it doing me good or not’ suggested that radiotherapy could be a potential harmful contaminant to the body, signalling disgust. Disgust has been consistently linked to the behavioural immune system, protecting against potential disease threats (see Oaten, Stevenson, & Case, 2009, for a review). Marianne goes on to describe a ‘weepy rash’ resulting from the treatment, a physical presentation of harm, as if to confirm her appraisal of radiotherapy as something not to be trusted. Also, the description of her bodily position, ‘arms in clamp’, and being unable to move while the radiation beam penetrates her body gives the sense of an act of violation. Marianne explained what she would think about during this process:

> I was just thinking I was riding one of me horses or [laughs]. You know, just getting away from the thought of what was happening, not thinking about it. And hearing the beams going and seeing the lights, I just tried to shut my mind off to it somehow.

Marianne’s narrative illustrates how she used dissociation strategies in order to keep the experience separate, as an act of protection, preventing it from penetrating her sense of self. Cognitive reappraisal and avoidance have been found to be strategies adopted when attempting to regulate the emotion of disgust (e.g., Olatunji, Berg, & Zhao, 2017; Reynolds et al., 2016).

Act 2 – ‘Something I’ve done’

The majority of stories contained narratives of externally directed and self-directed blame and guilt in which the narrator began to reflect on why they had cancer. Often these reflections involved previous life-style behaviours that conflicted with the dominant health narratives that suggest factors such as lack of good diet and exercise are associated with the risk of contracting some types of cancer. Marianne’s narrative describes her need to find an internal cause for her diagnosis:

> I was looking up what’s the causes…There's all sorts of things, even drinking red wine, you know too much of it. I do sort of drink too much, I know that, not so much since this actually, but...I was thinking 'It's probably my fault for drinking too much wine', or you know, something I've done, diet or...But I have a healthy diet.

Later in Marianne’s narrative, having described seeking internal causes for her cancer, she reveals a sense of guilt for some of the support she received from her friends and family: ‘I had to get my husband to drive me, because I'm no good at driving all that way and people had to take me to radiotherapy’, suggesting that Marianne perceived herself as a burden on other people.

Other narratives also suggested the pursuit of internal cause, leaving a sense of confusion at being diagnosed with cancer, particularly if lifestyle behaviours linked to cancer causality were absent: ‘Well you wonder why it happened? How it happened? And of course the 'Why me?'. I've never smoked, I don't drink. I like a social drink. Why does it happen?’ (Hazel)

Within his narrative Dave introduces the discourse of a health professional, perceived to be more knowledgeable, experienced and powerful on the subject of factors that prevent cancer reoccurrence. This narrative illustrates that despite the fact Dave does not specifically talk about guilt for contracting cancer, he alludes to internalised self-blame and guilt through his interest in preventative actions. Dave also feels responsible for preventing cancer, through adherence to lifestyle directives in accordance with dominate health discourses that locate disease risk within the individual.

Joan’s narrative describes how internalised messages of individual responsibility for health are felt and expressed in anger towards others who violate dominant health narratives:

> Anger, with people who abuse themselves when they've got everything going for them and they don't realise. Anger with people who drink, take drugs, and actually destroy their bodies, by choice. When there are so many people out there who would do everything, just to have the chance of doing that. Yes, I feel anger with them and I know it's a weakness, but yes. I see young women in the street…vastly overweight, smoking, with kids eating everything they shouldn't …

Joan’s narrative also eludes to disgust directed at others (socio-moral disgust). Her use of the phrase ‘destroy their bodies’ and how this occurs ‘smoking’ and being ‘vastly overweight’ give the sense of self–contamination in others. Consequently, Joan rejects the contaminated others, thereby protecting and maintaining the integrity of the self, particularly as smoking and obesity are considered to have cancer causing properties. Both smoking and obesity have been linked the emotion of disgust (e.g., Rozin & Singh, 1999; Vartanian, 2010).

Act 3 – 'That made me shudder'

The narratives of participants who experienced changes to their body as a result of surgery all describe scenes in which they first experience these changes and how they felt. A common feeling upon viewing themselves post-operatively was one of shock and feeling disgust. Joan describes a scene in which she was having a bath in hospital after her operation.

> I didn't know what to expect…And this nurse had helped put me in this bath and of course I hadn't seen anything and there was a mirror behind me, and I turned in the mirror on the wall and I'd got this blanket stitch! Black blanket stitch! You know, where I'd had a breast it was just flat to my chest and a blanket stitch! And I remember the shock of seeing it. (Joan)

Joan conveys feelings shock and disbelief. The repetition of the phrase 'blanket stitch' provides insight into the exact focus for Joan within the scene and her attempts to marry the image she sees with the body with which she was familiar. The description conveys a sense of loss, as Joan describes what is missing, 'a breast', then disgust at what was now occupying the area 'a black blanket stitch'. The type of stitch that Joan identified, a blanket stitch, is one that is associated with a use on a piece of material. Joan also focuses on the colour of stitch 'black', a colour that is in sharp contrast to the colour of her skin. Both the type of stitch and the colour are out of place; in this sense, this part of the body is now seen as out of place by Joan. Later in the narrative, Joan seeks a breast reconstruction in order to replace the alien part of the body (Douglas, 2002) with a more familiar and acceptable object, similar to her own breast, thereby reconciling this part of the body back into Joan's ownership.

Jules’ narrative expresses disgust as she describes more visceral responses on viewing her breast after surgery: ‘It just looks awful. It makes me sick looking at it now sometimes.’ The use of the word ‘sick’ highlighted that the subjective emotional experience of disgust goes beyond a cognitive one, instead the emotion is visceral and embodied. The bodily sensation of nausea is typically associated with the rejection of an undesirable or harmful ingested object and the emotion of disgust (Stern, Koch, & Andrews, 2011). The word ‘sick’ provides a sense of how Jules feels about her breast – an undesirable and potentially toxic part of her body. Nausea is a mechanism linked to the management of the indigestion of a potential toxin (Stern, Koch, & Andrews, 2011).

Jules’ story conveys that even more than 10 years after her surgery, she can still experience the changed area of her body in the same way suggesting little change over time: ‘It feels weird, even now it feels weird after all this time.’ This gives the sense that although the intensity of the emotion of disgust may have reduced, this part of the body still feels alien, causing distress, and remaining outside of Jules’ ownership. The word ‘weird’ indicates ‘matter out of place’ and therefore, an object of disgust (Douglas, 2002).

Jules describes how the changes to her body have affected other important characters in her life, in particular how it has changed intentions towards acts of intimacy: ‘…this thing with my boob, like the way it looks and everything, you know it was a bit off putting... I didn't really want to go with anybody, for that reason, you know.’ The language conveys both how Jules feels a sense of disgust about this part of herself, how this feeling is elaborated on to include how she perceives others will think of her body. Her use of the words ‘off putting’ suggests that others will view this part of her body as undesirable and therefore a barrier to sexual intimacy. There is also a sense that her changed breast has the power to contaminate, changing desirability to an untouchability that goes beyond her changed breast and encompasses her sexual self. As a result, Jules preferred to avoid others and the reminders of violated physical self.

Jules' narrative goes on to describe how she has experienced an act of intimacy. '…when they won't touch it... But even after I've done the comedy bit, they're still iffy about touching it...' Jules alludes to how she uses humour to manage both her feelings and the perceived feelings of her partner towards her changed breast. However, Jules' feelings of pain, shame and rejection are powerful and dominate the scene, as her attempts for this part of her body to be incorporated into acts of trust, connection and intimacy are thwarted. The scene also conveys how Jules interprets the reactions of her partner as confirming that a part of her is disgusting, leading her to further internalise part of the self as disgusting. Internalising reactions of others, interpreted disgust and rejection, has been demonstrated to lead to self-directed disgust (Powell, Overton & Simpson, 2014b), and, therefore, alludes to a schematic perspective of self-directed disgust.

Marianne's story also touches on concerns about the impact of her changed body on her relationship with her husband: 'Cause I can be negative. And he was fine. And the scars and everything, he doesn't mind at all, you know, it's not put him off sex or anything. Which some men I know it can do.' There is a sense that initially Marianne feels shame about her changed body. The phrase, 'which some men I know it can do' certainly alludes to Marianne's prevailing thought that it would bother men, and this probably extends to her husband, even though he is trying to show that it does not. Marianne's narrative illustrates her own negative appraisal of her changed body and how the reactions of her partner have been important in helping her cope with her changed body, preventing any initial feelings of shame or disgust from becoming deep-rooted. As well as self-directed disgust in people with cancer, disgust sensitive of partners has also been linked to poorer psychological wellbeing (Azlan et al., in press).

Hazel’s story reveals how she adapted to the sound of her voice post operatively. Initially, she used a valve and then a digital speech aid after her laryngectomy. Hazel describes when she first heard someone speak with a valve, shortly before having a valve fitted herself:

> They came along to talk to me and I realised they can speak and it was enlightening to find that it wasn't all gloom and doom... But they had a valve in and chatted away to me. But it was the sound of it that made me shudder…It didn't sound natural. It wasn't a natural voice…I think my mind was sort of in a bit a turmoil and I was getting used to the idea that I wouldn't sound like I did six months ago. I would be different. Would people accept me with a different sort of voice almost?

Hazel’s descriptions and the use of the word ‘turmoil’ gave the sense of her battling to come to terms with the loss of her voice and the realisation that her life would be different after her laryngectomy. Her thoughts then move on to question how relationships with people might be affected as a result of using a voice aid, particularly if Hazel’s first reaction was to ‘shudder’, suggesting a visceral, aversive response to the voice that did not sound ‘natural’. The violation of naturalness indicates feelings of disgust in this part of the narrative.

Hazel goes on to describe occasions when she is out in public:

> It's like going into a supermarket and speaking to my husband, you get people looking around, thinking ‘what's that strange noise?’ Now it doesn't bother me, and if children come up and I go, yes I have to speak like this. It worried me more then. I used to hide this [points to neck]. I used to wear neck scarfs…to hide the fact ... It's not only mentally, it's physical as well, the actual appearance. My husband used to say, ‘well you don't notice it’. But I say, ‘you may not, you're used to it, but people that you don't know DO [emphasis] notice’.

Within this description Hazel's language conveys how she has adapted to going out in public, alluding to a sense of felt shame. She notes that, despite reassurances from supportive family members, people unknown to her do notice her voice and neck, resulting from surgery. The emphasis on the word 'DO' indicates that there is no doubt in Hazel's mind that others will view her differently, separating her from typical social interactions and leaving her open to scrutiny. The use of the word 'strange' also alludes to a sense of others finding Hazel disgusting, as a result of her voice sounding 'mechanical' (violation of naturalness). Hazel pre-empts the negative evaluations and rejection, behaviours of enacted stigma, based on both her appearance and sound of her voice. This narrative is conducive with the perspective of self-disgust as a schema, as Hazel's appraisal of herself, past experiences and interpretations, lead her to conclude that others would find her disgusting.

Act 4 - 'It never really goes away'

A common act within all the participant stories was that, having had cancer, their lives changed in many different ways as a result. Many participants' stories illustrated how the body was feared, due to the continued concern of cancer reoccurrence. In this sense, the unpredictability of the future lead to a constant sense of fear and anxiety. Furthermore, there were indicators that cancer had occupied the body and changed the self, leading to a sense that the body could not be trusted and that it had the potential to silently harbour a deadly toxin.

> I suppose it's just seeing it like, that was an enemy that you've knocked out, but don't turn your back on it because it might come up and stab you in the back again, you know. So, you're aware of it. (Dave)

The use of the phrase 'stab you in the back' alludes to a sense of cancer taking you by surprise and that it is violent and potentially deadly. The language in Dave's narrative gives a sense that cancer is to be legitimately feared, as its intention is to kill you by your own body.

His body had betrayed him and is never to be trusted, in this sense there is a changed relationship with the self. Dave's narrative also gives the impression that he is alone with cancer and only he and not his body (as it has the potential to deceive, by silently harbouring cancer) can defend against it, again alluding to a sense of personal responsibility for containing the disease. Dave's narrative gives the sense of anxiety, leading to hyper-vigilance for signs of cancer having returned.

Anxiety generated by potential reoccurrence of cancer manifested itself in a number of ways. Unexplained aches and pains, that before being diagnosed with cancer did not cause concern, prompted anxiety that they may signal the return of cancer: 'Oh yeah, every ache and pain I think 'Oh dear'.' (Marianne) This narrative also gives the sense that body can no longer be trusted, indicating that the anxiety is in part related to the body's potential to be contaminated and alludes to emotion of fear directed towards the body itself.

Hazel's narrative explicitly indicates fear: 'And then there's always the fear I think of… something more involved,... was it primary cancer, was it secondary cancer... you get a lot of very conflicting things in your head about it.'. The narrative alludes to a sense of fear always being present. Her use of the phrase 'conflicting things in your head' indicates a form of battle between cognitive appraisals associated with threat and reassurance as she attempts to manage fear.

Other participants described how cancer had impacted on their lives to the point that it had changed their interests. All participants were part of cancer groups that met regularly and were involved in helping other people with a cancer diagnosis. Jules and Dennis both describe how, since having cancer, they enjoyed attending groups, an action that they would not have done before. Dennis illustrated how he has invested in helping other people with cancer at a wider systems level and at local support groups. In order to guide medical services, Dennis described how he was involved in peer reviews of cancer services, using his skills and abilities obtained pre-cancer diagnosed, as well as his experiences as a cancer patient. These narratives illustrate actions related to keeping cancer close, in some respects, this may be seen as an act of guarding against cancer. The body has the potential to harbour a toxin, therefore the body can be an object to be feared. The acts that keep the cancer close to the self (social groups, etc.), can be perceived as strategies that seek to manage anxiety, not only by gaining a sense of control over the threat of cancer, but also reconciling the feared body back into the ownership of the self.

Discussion

The narratives revealed a range of difficult emotions throughout the cancer treatment journey. The effects of having a cancer diagnosis on the lives of the participants were varied and far reaching, affecting all areas of their lives. The changes to participants' sense of self post cancer compared to pre cancer dominated all of the narratives.

As well as similarities across the narratives, differences across narratives were illustrated. Later in the cancer journey emotional experiences differed, particularly those relating to changes of the body as a result of cancer treatment. This was consistent with other studies involving visible difference (e.g. Rumsey, Clarke, White, Wyn-Williams, & Garlick, 2004) and head and neck cancer (see Lang, Frances, Williams, Humphris, & Wells, 2013, for a meta-synthesis), in which physical changes resulted in long lasting difficulties particularly with social interactions including intimacy. The emotional experience of participants converged around concerns of changes to bodies as a result of surgery and the impact of these changes on their lives going forward. However, the narratives differed qualitatively in the type and impact of difficult emotions after surgery. Within some narratives adaptation to and acceptance of the changed body was quickly reached. However, in other narratives, stigma both 'felt' and 'enacted' continued for a substantial length of time, throughout the stories and up to the time of interview. Interestingly, these narratives contained visceral responses in reaction to their changed body image, signalling disgust directed at the self.

From a theoretical perspective, the relationship between cognitions and emotions can be complex, taking on multi-level processing. One model that has conceptualised multi-level processing is the SPAARS model (Power & Dalgleish, 1999), who purport that emotion is a ‘holistic’ concept which includes an event, interpretation, appraisal, awareness and subsequent behaviour and has two routes of processing (associative and schematic). Of particular interest is the schematic level of processing, which suggest that emotional schemas are shaped by learning, experience and culture, which form part of child development. However, it has been hypothesised that physical aspects of oneself can activate self-disgust (Reynolds, et al., 2015), and furthermore, that dysfunctional self-disgust schema can be created in adulthood (Powell, et al., 2014a). Indeed some of the narratives illustrate this theoretical perspective, indicating that self-disgust schema could not only be activated but initiated by a physical change.

However, some, but not all, physical change led to development or even demonstrated self-directed disgust. This perhaps further strengthens the evidence for a schema perspective of disgust, as the presence of an event alone (i.e. physical change) did not automatically lead to the emotion of disgust. It was more a process of interpretation and appraisal based on an interplay of sociocultural and individual characteristics and resources.

A number of theoretical explanations may provide insight for the lack of narrative illustration of disgust activated through chemotherapy, a treatment in which core disgust elicitors are plentiful. Self-disgust may have been elicited by the side-effects of chemotherapy, particularly as descriptions of the side-effects were present within the narrative, however it may have been in an adaptive and constrained way, beneficial to the context, in that it acted to protect from threats of infection by limiting social contact while the immune system was comprised. Indeed protective aspects of self-disgust have been suggested theoretically (Reynolds, et al., 2015) and found empirically, for example in wound care management (Gaind, Clarke, & Butler, 2011).

Furthermore, if disgust responses are activated for a beneficial period of time (i.e. to reduce contact with potential contaminants), perhaps self-disgust as a schema within itself is not maladaptive, but rather the potential problem lies in the length of time that it remains activated. If disgust responses continue beyond a period where they are useful for protection, its effects are likely to be more deleterious than beneficial, particularly in relation to social avoidance. Certainly it may be fruitful for future research to investigate diverging disgust hypotheses, in order to test theoretical perspectives and inform clinical interventions.

However, the narratives did allude to radiotherapy eliciting disgust responses. These responses arose specifically from cognitive appraisal of the potential harm from the radiotherapy beam entering the body. In terms of clinical implications resulting from this finding, it may be worth exploring cognitive reappraisal strategies for those undertaking radiotherapy, which may prove more beneficial than thought suppression which has been associated greater emotional distress (Olatunji, Berg & Zhao, 2017).

More notably, the external and internal attribution of blame, associated with feelings of guilt and shame, was featured within almost all the narratives with this study, suggesting that previous lifestyle behaviours may have caused their cancer. Using the UK as an exemplar, although there are many other countries where similar examples can be found (see Raphel & Bryant, 2006, for a review), lifestyle factors dominate health promotion narratives. For example, UK cancer organisations suggest lifestyle behaviours such as smoking, activity, alcohol and diet all affect the risk of developing cancer, and go on to suggest that 4 out of 10 cancers could be prevented as a result (Cancer Research UK, 2016). However, who is responsible for the promotion of health and where the responsibility for determinates of health lie are a source of much political debate, but broadly fall into two models: individualised, where the focus is on biological factors, and structural, in which the impact of society organisation and influences are considered key (Raphael & Bryant, 2006). Although the policies of more recent UK governments have started to consider the impact of social disadvantage on health (e.g. Choosing health: Making healthy choices easier, Department of Health, 2004) many government funded media health campaigns still tend to focus on individual lifestyle behaviours, such as smoking and its links to the disease, in order to encourage behavioural change. However, for those already with a cancer diagnosis, this may contribute to a sense of personal responsibility for contracting the disease, which in turn can encourage societal narratives that support this view.

Encouragingly, all the narratives demonstrated a new sense of self develop after a period of disruption, worry and uncertainty. Similar experiences have been illustrated in long term conditions generally (Charmaz, 1991). Charmaz views social relations as a source of development and maintenance of the self in chronic illness. As such, reactions of others can diminish or develop an individual's sense of self. In terms of the narratives featured in this study, being part of cancer support and self-management groups provided an opportunity to engage in meaningful social interactions, and was an important part of developing a new sense of self.

However, support group membership and the extent of cancer severity, type of cancer and range of physical change did not dictate the nature and intensity of emotions and the subsequent responses to these emotions (i.e., avoidance). Within the narratives there are indicators of how various strategies are adopted and resources available to individuals are used, particularly in relation to supportive relationships with spouses and friends, as well as drawing up on previous experiences to overcome demands and challenges of having cancer. Some narratives, however, highlighted the impact of more difficult relationships and stressors, indicating that these could have an impact on emotional experience beyond cancer descriptors and support group membership. In this regard, it is important for cancer services and health professionals to consider the unique perspectives and resources of individuals, as some people will need more individually tailored support than a standardised approach offers. However, others may find inventions unnecessary and even an unwelcomed interruption to their recovery, regardless of cancer type and severity.

Moreover, difficult emotions, particularly those directed at the self may have implications for the development and maintenance of individuals' sense of self throughout and post cancer treatment. In this regard, health care professionals who have an understanding of the influence of self-directed emotions that lead to avoidance are better placed to recognise, support and manage individuals who are experiencing these emotions.

In terms of the limitations, it is important to note that a small number of participants took part in this study. However, due to the depth of the narratives, ways in which difficult emotions are experienced within the cancer treatment journey and how the self may be changed as a result are illustrated and therefore discussed in relation to theoretical perspectives. Furthermore, all the participants were recruited via support groups related to cancer, therefore there may be differences in narratives between group attendees versus non attendees, especially as the stories of the participants in this study indicated that group membership was an important part of their cancer journey, particularly in gaining a social network and acceptance. However, the illustrations highlighted within this study of how group membership supports and shapes sense of self is interesting, especially when considering clinical implications and interventions. Nonetheless, it should be noted that support group membership might not be beneficial for all. For example, a qualitative study of people with a Parkinson's disease diagnosis, exploring group membership, demonstrated that non-group members found the idea of group membership distressing, preferring to use other coping mechanisms (Charlton & Barrow, 2002).

In conclusion, analysis of these narratives demonstrate that difficult emotions directed at the self could manifest at different times and in different ways. They could be enduring, affecting sense of self and daily living. It is important to recognise and understand these emotions in order to create and shape individualised support and interventions for people struggling to reach a new sense of self. In this regard, more qualitative research is needed in order to help researchers, health professionals and services to further understand the processes of difficult self-directed emotions.

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Table I. Summary participant demographics.

Name	Age	Ethnicity	Primary cancer diagnosis	Cancer treatment type	Duration of treatment	Age of onset	Time lapse since active treatment
Dave	77	White British	Non-Hodgkin's Lymphoma	Surgical Removal & Chemotherapy	7 months	74	2 years
Hazel	74	White British	Vocal Chord	Surgical Removal & Radiotherapy	4 months	64	10 years
Jules	68	White British	Breast	Lumpectomy & Radiotherapy	6 months	57	10 years
Dennis	68	White British	Prostate	Radical prostatectomy	2 months	58	10 years
Joan	74	White British	Cervix	Surgery	2 weeks	37	12 years
Marianne	64	White British	Breast	Lumpectomy & Radiotherapy	4 months	64	10 months

Appendices

Appendix A

Sample transcription

Interviewer: Can you tell me how you felt about yourself throughout your cancer journey?

Interviewee: Annoyed [laughs]. Annoyed because I didn't want it to happen. Upset initially and then a bit sort of euphoric as it when on, you know. Trying to put it to the back of my mind, I think.

Interviewer: Which bits were you more upset, at the beginning?

Interviewee: The beginning yeah and thinking, 'Oh it'll just spread', you know. I had a strange feeling as well when I had the mammogram, I sort of knew, even though there wasn't a lump. I got letter through the door to go to back and I said 'I knew this was going to happen'. I just had it in my head somehow.

Interviewer: So was it a standard screening mammogram?

Interviewee: Yeah just normal. A 3 year one, yeah.

Interviewer: Did you feel anything had changed in your body?

Interviewee: No, no. Cause it wasn't an actual lump, it was... they called it a mass, more than anything.

Interviewer: So what did you feel when you hear that, the idea of a mass.

Interviewee: Well I was horrified. I didn't like it. I just wanted to get the operation done. So it was actually 3 weeks before I had it done, because I had to have a erm...What's it called as wire led... Wire lead into the breast, so the surgeon could see where the lump was, because it was more inside than outside. So the radiologist had to do that, so he wasn't available for 3 weeks. So I had 3 weeks were I was quite upset, you know worrying about.

Interviewer: So you were upset at the idea of...

Interviewee: Having the cancer and has it spread, and... Because I don't...I've had a few friends that have had cancer and their not here now so.

Interviewer: I was going to ask what your previous experience of cancer was.

Appendix B

Example of a grouped concept (Something I've done)

Dave	Hazel	Jules	Dennis	Joan	Marianne
Yeah, and they were only in their early 60's. My mother died first, she had breast cancer. Then my Dad died of bowel cancer, 18 months later. So it's not a well liked disease in my family. Well it's not a well liked disease in any family! (p8)	: Not really. You take good health for granted, it's only when things start going wrong or went wrong that you realise we're all vulnerable one way or another. Because I mean I never smoked and I was told initially, it's a smokers' cancer. It's often associated with people who smoke a lot. I don't smoke, I never have smoked, so... (p5)	Well we actually went into that about, you know, whether it would be carried on because there was nothing in the family beforehand to suggest cancer was in the family and I think as far as I know everything was ok with that, you know. It was like a one off kind of thing. They did say it was lifestyle. I don't know what they say by lifestyle, what that means? I had too much ice cream probably, you know (laughs).		And I had a lot of stress at work, so I put the stress... I also think the stress, plus the fact I was given HRT, and one of things the doctor did say afterwards, cause I said, 'Could this have been...' I had it for 3 months and I just bleed. I just said, 'could it have affected it', I said 'Could it affect it?' (p2)	Oh I was looking all sorts up! As you do, yeah, yeah. [laughs] All different kinds of cancer and....Mine was called ductal cancer, which was in the milk ducts, and he asked me if I'd breastfed and I said 'Yeah, is that a good thing or a bad thing?'. He said 'Oh I don't know really'. So you think should I have breastfed or...? He wasn't committing. (p6)

Appendix C

Sample advertisement

Health & Medicine | Lancaster University

Have you experienced difficult emotions about yourself during your cancer treatment journey?

As a result of the experience of being diagnosed and treated for cancer, some people can find that they experience difficult feelings about themselves - feelings such as guilt, shame or disgust.

If you have experienced these feelings, are not having active treatment, and are over 18 years old, I would love to hear your story.

For more information visit *insert link to PIS*. Or please contact me on:-

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Appendix D

Participant information sheet

Health & Medicine | Lancaster University

Participant Information Sheet

Understanding difficult emotions about yourself in the cancer treatment journey

My name is Selane Rigby and I am conducting a study as a trainee clinical psychologist at Lancaster University, Lancaster, United Kingdom. I am interested in the feelings people have about themselves during cancer treatment. I am looking for volunteers to take part in a study which will involve talking to me on a one to one basis about these feelings. However, before making any decisions about whether you might want to be interviewed, I would like to ask that you read the study information below, to ensure that any decision to participate is right for you.

What is the study about?

The study is concerned with how we feel about ourselves during treatment for any cancer. How we feel about ourselves can affect how we are able to live our lives or behave. Some people can find that they experience difficult feelings, such as guilt, shame, or disgust about themselves, throughout the course of their cancer treatment.

People who experience difficult emotions about themselves can, at times, think of themselves in negative ways and can also feel that others avoid them as a result. I am interested in the personal stories of people who have experienced these emotions at any point within their cancer treatment journey.

Why have I been approached?

You have been approached because the study requires information from people who: -

- have experienced difficult emotions about themselves (described above)
- are over the age of 18
- are no longer in active treatment for cancer.

Do I have to take part?

No. It’s completely up to you to decide whether or not you take part. The researcher is completely independent from any organisation involved in your care and your decision whether or not to take part will not affect any services you receive in any way. If you do decide to take part, but then change your mind, you can withdraw from the study up to the point when the research is written up ready for submission.

What will I be asked to do if I take part?

If you decide you would like to take part, you would be asked to take part in an interview at a time and date and venue to suit you. I will ask if you have any special requirements before the interview to make your experience comfortable. The interview will be recorded, with your permission, on a dictaphone and will usually last around 60 minutes. You will be asked to share your story about your experience of emotions throughout your cancer journey. It will be up to you to decide how much or little you would like share. At the end of the interview you will have a chance to ask questions and feed back your experience of the interview. The interview will then be typed up by the interviewer. Any information that could lead yourself or others being identified will be anonymised.

Will my data be identifiable?

The information you provide is confidential. Direct quotes from participants in this study may be used when it is written into a report. The source of the quote will not be attributed to you. The interview will be turned into a written account and will be stored securely and only the researchers conducting this study will have access to it:

- Audio recordings will be destroyed and/or deleted once the project has been submitted for publication/examined.
- The computer files will be encrypted (that is no-one other than myself will be able to access them) and assess to university computers will be password protected.
- At the end of the study, electronic copies of transcripts will be kept securely for ten years. At the end of this period, they will be destroyed.
- The typed version of your interview will be made anonymous by removing any identifying information and replacing your name with a pseudonym of your choosing. Anonymised direct quotations from your interview may be used in the reports or publications from the study. If this happens, a pseudonym name will be attached to them.
- All your personal data will be confidential and will be kept separately from your interview responses.

There are some limits to confidentiality: if what is said in the interview makes me think that you, or someone else, is at significant risk of harm, I will have to break confidentiality and speak to my supervisor about this. This will be discussed with you, though.

What will happen to the results?

The results will be summarised and reported in a dissertation/thesis. The results of the research may be submitted for publication in an academic or professional journal. A summary of the results will be made available for participants who would like these.

Are there any risks?

There are no risks anticipated with participating in this study. However, if you experience any distress following participation you are encouraged to inform the researcher and contact the resources provided at the end of this sheet.

Are there any benefits to taking part?

Although you may find participating interesting, there are no direct benefits in taking part. However the information from this study may lead to benefit others who face the cancer journey and health professionals working with people also affected.

Who has reviewed the project?

This study has been reviewed and approved by the Faculty of Health and Medicine Research Ethics Committee, at Lancaster University.

Where can I obtain further information about the study if I need it?

If you have any questions about the study, please contact the main researcher:

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Faculty of Health and Medicine
(Division of Health Research)
Lancaster University
Lancaster
LA1 4YG

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Professor Bill Selwood Tel: (01524) 593998 Email: b.sellwood@lancaster.ac.uk
Doctorate in Clinical Psychology Programme Director
Division of Health Research
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If you wish to speak to someone outside of the Division, you may also contact:

Professor Roger Pickup Tel: +44 (0)1524 593746 Email: r.pickup@lancaster.ac.uk
Chair of the Faculty of Health and Medicine Research Ethics Committee
Faculty of Health and Medicine
(Division of Biomedical and Life Sciences)
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Thank you for taking the time to read this information sheet.

Resources in the event of distress

Should you feel distressed either as a result of taking part, or in the future, the following resources may be of assistance:

Contact your GP or Health Care Professional who works with you. You may wish to contact MIND (available Monday to Friday, 9am to 6pm) 0300 123 3393 or visit www.mind.org.uk. Or Macmillan Cancer Support (available Monday to Friday, 9am-8pm) 0808 808 00 00 or visit www.macmillan.org.uk. Alternatively, you can contact regional cancer charities and support groups, Cancercare on 01524 381820 (24 hour answer service) or visit www.cancercare.org.uk, The Rosemere Foundation Trust on 01772 522 913 or visit www.rosemere.org.uk, and Gentle Approach on 01772 865024 or visit www.gentleapproach.org.uk.

Thesis Section 3: Critical Appraisal

Researching Emotions: The Ups and Downs.

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Doctorate in Clinical Psychology

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The thematic synthesis contained in the literature review section explores the many emotional experiences involved in cancer treatment at specific transition points within the individual's journey. The findings synthesised within temporally sequenced framework, based on transition points throughout the journey: Being diagnosed and facing treatment; Getting rid of cancer; Changed body and stigma; Reflections on the emotional journey having completed treatment. The emotional experience changed rapidly at diagnosis, followed by a period of fewer and more stable emotions during treatment. The period post treatment signalled anger and sadness associated with loss. Finally, life after cancer demonstrated emotional reconciliation and benefit finding.

The research paper specifically investigates self-conscious emotions and both their evolution over time and their impact on sense of self. Four temporally ordered acts emerged that provided demonstrations of self-directed difficult emotions of disgust, guilt, shame and fear and how and when these emotional experience changed the self.

The findings from both papers overlap in the sense that emotional experiences are complex and nuanced. Many factors, such as relationships, current stressors, past experiences and resources (personal and systemic) can impact on emotional experiences. Moreover, not only are emotional experiences numerous and nuanced, the theories, and indeed the methods by which emotions can be studied, are complex. This paper offers a discussion around some of the considerations and insights involved in the research of emotions, in relation to my research studies and the study of emotions more widely. It also outlines some of the strengths and weaknesses of the research presented, in light of this discussion.

One of the main issues relating to studying emotion has been a lack of consensus about what constitutes an emotion and the nature of emotion (Lupton, 1998). For example, Ekman (1992) proposed a biologically driven theory identifying six basic emotions (happiness, fear, anger, sadness, disgust, sadness and surprise). However, other theorists suggest that there are many more emotions, although these are generally thought to be combinations of the aforementioned basic emotions, for example, contempt is a blend of anger and disgust (Plutchik, Kellerman, & Conte, 1979). In contrast other theories, grounded in a social constructionist epistemology, such as situationism, suggest that emotions are founded and produced at a societal and environmental level and are used for skilful social communication (Griffiths & Scarantino, 2005).

Obviously, lack of agreement regarding emotions and their nature has further implications for research methodology, particularly, for more positivist approaches that prefer measurement and objectivity. Beyond measurement of specifically defined emotions, positivist approaches can be somewhat limited in considering social variables. In this regard, emotions can be viewed as elusive and complex, as they do not lend themselves to more traditional research methods, such as experimental designs (Zembylas, 2007). In contrast, social constructionist methodology, which privileges societal factors in the construction of emotions, such as political and cultural norms, run the risk of not considering an individual's embodied experience. As a result of the many theoretical and methodological approaches to the study of emotions, the naive researcher, in which category I would include myself, should perhaps proceed with caution. In particular, this caution pertains to how much we can risk neglecting in the research of emotions should we choose one approach to emotion research over another. Indeed, how much we can learn by only pursuing one approach and thereby accepting a narrow perspective, might be considered reductionist in itself, regardless of epistemological stance. However, even the naïve researcher must proceed, despite difficulties in researching emotions, particularly as emotion is viewed as a key part of what it is to be human. Denzin, (1984) makes this point eloquently:

> Emotionality lies at the intersection of the person and society, for all persons are joined to their societies through the self-feelings and emotions they feel and

> experience on a daily basis. This is the reason the study of emotionality must occupy a central place in all the human disciplines, for to be human is to be emotional. (p. x)

In consideration of the many complexities involved in the study of emotions, not least how to transcend existing dichotomies (mind or body, feeling or meaning), the task of operationalising emotional phenomena or experiences is a difficult one. For example, it is unlikely that participants in interview scenarios would express their emotional experiences in terms of the six basic emotions. Instead, interviews rely on emotional expression to be conveyed through common parlance that is likely to be culturally and contextually informed, (although not only socially driven). In this context emotional experience is likely to be conveyed not just through language, but through bodily expression (crying, closing eyes, shaking, etc.). Furthermore, others discursive devices, such as metaphors and comparisons, are likely be used to convey emotional experiences. For example, in my own research painful emotions were eluded to through relaying a comparatively similar event, with a different outcome. Dave told me about an event that happened shortly after the death of his wife:

> And just within 2-3 months the dog became really ill and had cancer, and was really sort of terminal. It was bad. And I had make the decision, you know, to have her put down, you know. And er, I said I'm not taking her to the vets. And I won't. And I paid for the vet to come here [home], because I couldn't do it for my wife to be here at home, she had to die in hospital, so I'm not going to do it for her dog. So the vet came and all the family came round and he dealt with her here. Which was better for all of us really. At least we could do something. Because we all loved the dog and as I say, it was my wife's dog mainly so. Yeah so that was…Yeah, because it's not pleasant to see somebody die in hospital, you know. You'd rather it be in their own surroundings if possible, but I wasn't able to do that.

Within the passage, Dave finds it easier to talk about a situation in which the subject of dying was still at the centre, but for which Dave was able to control the setting and contribute to what he had considered to be a dignified death. Many actions within the narratives required interpretation, in order to illustrate the underlying emotions. For example, Dave's actions may indicate feelings of guilt, at not being able to provide the environment he had wished his wife had at her passing.

Interpreting underlying emotions from the narratives leave the analysis open to criticism concerning credibility. Certainly the construction of the act and responsibility for the analysis, including which parts of the narratives to incorporate within the findings and how this discourse is interpreted, can indeed be viewed as subjective. In fact, the analysis should be viewed as co-constructed and therefore subjective. In part, the subjectivity of the analysis, providing that it is acknowledged, may be viewed as a strength and this may be particularly so in the research of emotions. This is because one of emotion's most likely functions is communication therefore emotions felt by the researcher in the relational interplay may equally offer insight into participants' emotional experience. Indeed, some researchers use the term 'hidden ethnography' to refer to emotions evoked in researchers, particularly when investigating difficult topics. However, the 'hidden' aspect relates to research conventions either not accommodating or actively prohibiting the emotional experience of the researcher to be incorporated into the completed research (Blackman, 2007). In contrast, Lee-Treweek and Linkogle (2000) conclude: 'the emotions of research are important to both the researcher's ability to cope and the quality of the account they produce. Ignoring or repressing feelings about research is more likely to produce distortion of data, rather than clarity' (p. 128). Punch (2012) goes further, suggesting that the use of extracts from field diaries that record the emotions and feelings of the researcher be explicitly incorporated into research.

Certainly, within my own research journey, the parts of my participants' interviews that I recall the best are those that evoked an emotional reaction from me. For example, Hazel, who had had a laryngectomy – the removal of her voice box - requested that I record her voice before we start the interview in order that she could assure herself that the recorder would be able to pick up her speech. I recall two key moments within this interaction. Firstly, her bodily reactions upon listening back to her recorded voice. Secondly, her asking me 'Do I really sound like that? It's awful'. Both of these events were ones in which I felt Hazel's disgust at the sound of her own voice, particularly her bodily reactions to hearing her recorded voice in which she closed her eyes and put her hand to her mouth (a classic disgust behavioural response). Clearly, these events were beyond capturing in the voice recording and subsequent transcription process. However, my experience alerted me to Hazel's underlying emotions regarding her voice. My own emotional experiences with Hazel and other participants throughout my research, influenced how I interpreted the narratives. In this respect, the analysis of the narratives not only allows us to see emotions in the context of what has caused them, how they are experienced (both felt and embodied), and subsequent actions, but also as a co-construction in which the emotions of the researcher to the material are illustrated.

Moreover, researching difficult emotions, and in particular disgust, may have taken on a taboo of its own, not unlike the reactions encapsulated by the disgust response. Certainly, in different fields and perspectives, disgust takes on different forms and means. For example, in the field of academia the understanding and meaning of disgust takes it underpinnings from definitions, such as that offered by Rozin and Fallon (1987), who clarify disgust as: 'revulsion at the prospect of (oral) incorporation of an offensive object. The offensive objects are contaminants; that is, if they even briefly contact an acceptable food, they tend to render that food unacceptable' (p.23). However, within the general population the word disgust has been found to be more synonymous with anger, with the lay person's term 'grossed out' a closer match to the theoretical meaning of disgust (Nabi, 2002).

Moreover, the interest in disgust, which can often be an adaptive response to stimuli from a researcher's perspective, does not always hold the same meaning both within the general and, more specifically, the cancer population. In fact, during the course of my own research, while in communication with a cancer charity, I received the following email in response to sending them the study information materials:

> The following is offered for information only, and is offered from a lay person - albeit from someone who has worked very closely with cancer patients over more than 15 years – so has no psychological credentials behind it.
>
> Some of the language used by researchers can sometime be a barrier to participation in research. Last year we had agreed (with the Group) that a researcher was going to do some work with the Group that meets at our …around three times a year for blocks of yoga sessions. Unfortunately after the first session with the Researcher within the Group, we found that we lost a number of the participants in the Yoga Group. The week after even more decided not to come and we were informed that there would be even less if this continued. So we halted the research.
>
> I say this as one of the words that was being used within that research and which seemed to be unhelpful was "disgust" and "self-disgust". This is a really strong word and whilst may in fact be an accurate indicator of what someone is feeling, can be difficult for people to acknowledge – especially when they are "surviving" and trying to remain positive.

Indeed, this gives much food for thought, particularly if disgust or self-disgust 'can be difficult for people to acknowledge'. Incorporating this feedback into my own research brought with it many tensions. Primarily, how was disgust or self-disgust going to be brought out in the narratives, particularly as a narrative approach offers the narrator (participant) the space to tell their story in their own terms, and therefore, they are unlikely to use the word disgust by choice. In order to navigate this particular tension, the narratives relied on my interpretations based on my knowledge of how emotions, such as disgust, may present themselves in actions and cognitions, as these were more likely to be represented in the participants' language than naming the underlying emotion per se.

Furthermore, inferred in the email were themes of 'positive psychology' and what is permitted in cancer recovery, in particular, 'remaining positive'. Ideas of 'positive thinking' have permeated cancer care since the 1990's (e.g. Gray & Doan, 1990) and form part of the current dominant narrative among the cancer community (McCreaddie, Payne & Froggatt, 2010). However, positive thinking is not without its critics, most notably Wilkinson and Kitzinger (2000), who take a social constructivist perspective on the issue of positive thinking in cancer. They suggest that people make meaning through their understanding of the 'rules' within a social context, and go on to infer that although an individual may say that they are 'thinking positively', that does mean that they do think 'positively', rather these are echoes of the inferred rules of group or social membership. Understandably then, a researcher interested in difficult emotions, which could be conceived as representing potentially 'negative thinking' and therefore in contradiction of the social rules, is likely to receive a lukewarm response.

Moreover, would the narratives in my own research be peppered by 'positivity' talk that conforms to the current dominant discourse of cancer recovery? Indeed, there was some evidence of positive thinking within the narratives. Here a participant talks about their cancer recovery citing the need to obtain a 'positive attitude':

> I wasn't powerless. I couldn't do anything about the cancer, obviously that was the surgeons, but I could do something about getting fit again, and getting a positive attitude to it and dealing with the physical side of chemo and everything.

Obviously, the acceptability and dominance of positivity adds an additional layer when attempting to uncover more difficult emotions within the narratives. The point here is not that people do not feel positive, indeed in my own literature review, as in other studies (e.g., post-traumatic growth, Foley et al., 2006), many participants cited a renewed sense of self, but if the dominant discourse only allows for positive thinking, this may result in marginalising people who are unable to embody this mind set. In this regard, research that seeks to explore difficult emotions is not only timely but relevant, given that marginalised groups are those more likely to require support.

From the beginning of the research process, difficult emotions, again with particular focus on disgust, raised many concerns. Ethical considerations around the practicalities of researching disgust were prevalent and took on a number of forms. Initially, the definition used in the participant information sheet took on elements from the Self-Disgust Scale Revised (SDS-R) (Powell, Overton & Simpson, 2014) and read as follows:

> One emotion of particular interest is that of disgust, which has been identified as potentially both a cause of psychological distress during cancer treatment and a reaction to the treatment. People who experience feelings of disgust can find themselves repulsive, can’t stand being themselves, or think that they are revolting for many reasons. People who feel this way about themselves can also feel that others avoid them, as a result.

However, due to concerns around the definition of disgust, in particular, not appealing to participants, the following definition was adopted:

> The study is concerned with how we feel about ourselves during treatment for any cancer. How we feel about ourselves can affect how we are able to live our lives or behave. Some people can find that they experience difficult feelings, such as guilt, shame, or disgust about themselves, throughout the course of their cancer treatment. People who experience difficult emotions about themselves can, at times, think of themselves in negative ways and can also feel that others avoid them as a result. I am interested in the personal stories of people who have experienced these emotions at any point within their cancer treatment journey.

Understandably and rightly, part of the research ethics committee's role is to ensure that research projects are viable. Indeed, the ethics committee made many helpful suggestions in order for study participation to be attractive. However, the more diluted version of the study definition (i.e. putting disgust within a string of other self-directed but less visceral emotions) had the impact of changing both the initial focus of the project, that of self-disgust, to difficult emotions more generally. Additionally, the amended version of the definition was more open to interpretation and, therefore, less targeted and ran the risk of participants taking part in study that did not necessarily match the study focus.

Moreover, other projects interested in the exploration of self-disgust have been able to use instruments, such as the SDS-R for quantitative studies, or to screen participants for qualitative projects. However, because of the research question and design, the participants I was interested in interviewing did not need to be currently experiencing self-disgust, but had needed to have experienced it at some point in their cancer journey. The SDS-R is sensitive to recent or present indicators of self-disgust, not to past (and now irrelevant) experiences of self-disgust, therefore rendering this instrument redundant as a screening tool. Again, use of a strong study definition and, therefore, correct participant interpretation of the nature of the study, was of paramount importance in order to attract people who had experienced self-disgust. However, as the study definition and therefore focus of the study had changed, it could not be assumed that participants had experienced self-disgust per se, rather the type of difficult emotions experienced needed to be teased out during the interviews. Clearly, not all participants had experienced self-directed disgust, which therefore changed the shape and direction of the study somewhat.

However, the narratives gained as a result of the study definition offered a great deal of insight into the nature and experience of self-directed difficult emotions, within the cancer journey. It is interesting to note that participants experienced similar processes and treatments, however, individual differences in how these are experienced, interpreted and appraised provides much insight into the richness and variation involved in emotions and their experience. Indeed, far from detracting from the focus of the research, the breadth and depth in the narratives provided indicators and demonstrations of not just when and how difficult emotions are experienced, but how and when they are overcome and, at times, how they can endure. Therefore, both the narratives illustrated within the research project and the literature review offer an insight into the variation, complexity and nuance of the emotional experiences during cancer and treatment processes, signposting future research and clinical directions.

In terms of clinical implications resulting from the papers, there are numerous indicators that health professionals need to assess and consider individual contextual factors before offering interventions. My research findings demonstrated that emotional experiences can evolve overtime, however, guidance focused on the management of distress that indicate early identification and intervention from the point of diagnosis, can run counter to these findings. Obviously, it is important to identify people who would benefit from support and interventions, but if a broad brush approach is taken, there is a risk of disrupting natural coping mechanisms (Baker et al., 2013). Moreover, more targeted and individualised assessment may also have the benefit of reducing unnecessary referrals of clinical support. For example, Dennis told me:

> They sent me to see a Clinical Psychologist...There was two of us me and this young lady. She had cancer. And we were both seeing the same rheumatologist. And he got this idea into his head, that if you had cancer, you must be depressed. So he referred us to this Clinical Psychologist and we laughed because we both got a letter saying we weren't depressed.

Clearly, a nuanced approach to assessment of those undertaking cancer treatment, which considers emotional transitions points within the cancer treatment journey and individual factors, such as current stressors and resources, needs to be adopted.

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Thesis Section 4: Ethics

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Faculty of Health and Medicine Research Ethics Committee (FHMREC) Lancaster University

Application for Ethical Approval for Research

for additional advice on completing this form, hover cursor over 'guidance'

Title of Project: The role of difficult emotions in the cancer treatment journey.

Name of applicant/researcher: Selane Rigby

ACP ID number (if applicable)*: N/A **Funding source (if applicable)** N/A

Grant code (if applicable): N/A

***If your project has *not* been costed on ACP, you will also need to complete the Governance Checklist [link].**

Type of study

☐ Involves existing documents/data only, or the evaluation of an existing project with no direct contact with human participants. **Complete sections one, *two* and four of this form**

☒ Includes *direct* involvement by human subjects. **Complete sections one, *three* and four of this form**

SECTION ONE

1. Appointment/position held by applicant and Division within FHM Trainee Clinical Psychologist

2. Contact information for applicant:
E-mail: s.rigby1@lancaster.ac.uk **Telephone**: xxxxxxxx (please give a number on which you can be contacted at short notice)
Address: xxxxxxx

3. **Names and appointments of all members of the research team (including degree where applicable)**

Selane Rigby, Trainee Clinical Psychologist
BSc (Hons) 2:1 Psychology
Msc Distinction Health Psychology

Dr Jane Simpson
Dr Philip Powell

PG Diploma ☐ Masters by research ☐ PhD Thesis ☐ PhD Pall. Care ☐

PhD Pub. Health ☐ PhD Org. Health & Well Being ☐ PhD Mental Health ☐ MD ☐

DClinPsy SRP ☐ [if SRP Service Evaluation, please also indicate here: ☐] DClinPsy Thesis ☒

4. Project supervisor(s), if different from applicant: Dr. Jane Simpson and Dr. Philip Powell

5. **Appointment held by supervisor(s) and institution(s) where based (if applicable)**: Dr Jane Simpson, Director of Education, Division of Health Research (Lancaster University) and Dr Philip Powell, Research Associate (Sheffield University)

SECTION TWO

Complete this section if your project involves existing documents/data only, or the evaluation of an existing project with no direct contact with human participants

1. Anticipated project dates (month and year) Start date: End date:

2. Please state the aims and objectives of the project (no more than 150 words, in lay-person's language):

Data Management

For additional guidance on data management, please go to [Research Data Management *web*]*page, or email the RDM support email:* rdm@lancaster.ac.uk

3. Please describe briefly the data or records to be studied, or the evaluation to be undertaken.

4a. How will any data or records be obtained?

4b. Will you be gathering data from websites, discussion forums and on-line 'chat-rooms' no

4c. If yes, where relevant has permission / agreement been secured from the website moderator? no

4d. If you are only using those sites that are open access and do not require registration, have you made your intentions clear to other site users? no

4e. If no, please give your reasons

5. What plans are in place for the storage, back-up, security and documentation of data (electronic, digital, paper, etc)? Please ensure that your plans comply with the Data Protection Act 1998.

6a. Is the secondary data you will be using in the public domain? no

6b. If NO, please indicate the original purpose for which the data was collected, and comment on whether consent was gathered for additional later use of the data.

Please answer the following question *only* if you have not completed a Data Management Plan for an external funder

7a. How will you share and preserve the data underpinning your publications for at least 10 years e.g. PURE?

7b. Are there any restrictions on sharing your data?

8. Confidentiality and Anonymity

a. Will you take the necessary steps to assure the anonymity of subjects, including in subsequent publications? yes

b. How will the confidentiality and anonymity of participants who provided the original data be maintained?

9. What are the plans for dissemination of findings from the research?

10. What other ethical considerations (if any), not previously noted on this application, do you think there are in the proposed study? How will these issues be addressed?

SECTION THREE

Complete this section if your project includes *direct* involvement by human subjects

1. Summary of research protocol in lay terms (indicative maximum length 150 words):

As self-disgust is a relatively new research topic, little guidance is available to clinicians working within long-term physical health conditions generally. One of the most prevalent physical health problems and a leading cause of death in England and Wales is cancer (Office for National Statistics, 2015). Moreover, recent studies using quantitative methodology has found that self-disgust is a mediator of psychological distress in adults with cancer (Powell, Azlan, Simpson, & Overton, 2016; Azlan, Overton, Simpson, & Powell, 2016). Consequently, the primary aim of this study is to investigate the story of self-disgust throughout the course of cancer treatment. The evidence from personal narratives can highlight when the self-disgust is most prominent within the cancer treatment journey and equally important when and how self-disgust becomes more dormant. The intended number of participants will be up to 15 people in order to obtain enough data for chapters or plots giving the narrative coherence, for the self-disgust story in cancer to emerge.

2. **Anticipated project dates**
(month and year only) Start date:
12/16 End
date09/17

Data Collection and Management

For additional guidance on data management, please go to Research Data Management *webpage, or email the*
RDM support email: rdm@lancaster.ac.uk

3. Please describe the sample of participants to be studied (including maximum & minimum number, age, gender):

Up to 15 participants will be recruited for the study. Once all reasonable options for recruitment have been exhausted and 15 participants have not been recruited, the study analysis will proceed with the number of participants obtained. Participants will be adults (18 years or older) who have had a cancer diagnosis (any) but are no longer in active treatment (i.e. radiotherapy/chemotherapy) at the time of interview. However they could be on less invasive treatments (e.g. hormone therapy with Tamoxifen). Participants cannot have a 'watch and wait' tumour diagnosis. Participants will identify with having experienced self-disgust at some point throughout the course of their cancer journey/treatment. Selection on the basis of gender will not form part of the recruitment process.

4. How will participants be recruited and from where? Be as specific as possible.

Participants will self identify as having experienced self-disgust by reading the explanation given in the study information sheet or study advertisement. They will be recruited from the community and will have been treated for at least one form of cancer. Regional cancer charities and support groups such as xxxxxxxx, xxxxxxx and xxxxxxxx, will be contacted by the lead researcher using a university telephone or email account. The organisation will be provided with a participant information sheet if initial contact is via email, or forwarded via email after an expression of interest on telephone contact. Any other information they wish to review, (i.e. ethical approval before promoting the study) will be sent via university email. If the organisation consents to advertising the study, all necessary materials will be sent. The promotion of the study by consenting organisations can be done via electronic media channels such as social media, website, email and online forums,as well as more traditional routes such as newsletters, word of mouth and notice boards. The advertisement and participant information sheet will contain the contact information of the researcher (university email and telephone) and will ask potential participants to contact the researcher directly.

5. Briefly describe your data collection and analysis methods, and the rationale for their use.

Demographics and information will be collected. The information collected will include age, gender, ethnicity, primary cancer diagnosis, type and duration of cancer treatment, age of onset and time elapsed since active treatment. Interviews will be conducted and recorded using a digital recorder. The applicant will transcribe and anonymise all interviews. The first interview will be read with the research supervisor to commonly agree that the content is applicable to the research question and ensure the quality of the research process. Narrative analysis will be used to analyse the interview data.

Given the nature of narrative analysis, in that it is interested in individuals' personal perspectives of their own story and sense of self by allowing space for the narrative to evolve, the interview will be mainly unstructured and will begin by asking the question 'Would you like to tell me about how you felt about yourself, throughout your cancer journey?'. However in order to maintain the focus of the research question, the researcher may ask questions to clarify a point, or to expand on an area of interest, from a neutral position. The interviews will be audio recorded and transcribed by the researcher.

Narrative analysis places emphasis on the interplay between self and context. The core element of this type of analysis is the uncovering of the self-construct, in particular how participants view themselves and how this view is shaped. Furthermore, it focuses on the process of shaping and the contributing factors (Weatherhead, 2011). This is a useful approach for answering the research question, in that is allows for in-depth exploration of the development of self-conscious emotions as part of the view of self, throughout the cancer treatment journey.

6. What plan is in place for the storage, back-up, security and documentation of data (electronic, digital, paper, etc.)? Please ensure that your plans comply with the Data Protection Act 1998.

Demographics collected from the recorded data will be stored electronically in a password protected file on Box (Lancaster University secure server). Any names and contact details will be stored in a separate password protected file, stored on box, and deleted once the summary of findings have been delivered and the study assessed.

The interview recordings will be transported and stored securely on Box. The recordings will be uploaded directly to Box (University secure server) from the digital recorder at the earliest opportunity and deleted from the recording device. Audio files of the interviews will be stored and deleted once the project has been assessed and completed. Scanned consent sheets and typed transcripts will be stored electronically on the Lancaster University server for 10 years. A member of the research team will be responsible for deleting the files after this time has elapsed.

7. Will audio or video recording take place? ☐ no ☒ audio ☐ video

a. Please confirm that portable devices (laptop, USB drive etc) will be encrypted where they are used for identifiable data. If it is not possible to encrypt your portable devices, please comment on the steps you will take to protect the data. The audio recording device does not have encryption functionality, therefore the interview recordings will be securely transported and uploaded directly from the digital recorder to Box at the earliest opportunity. The recording will then be deleted from the audio recording device immediately.

b What arrangements have been made for audio/video data storage? At what point in the research will tapes/digital recordings/files be destroyed?

The interview recordings will be transported and stored securely. The recordings will be uploaded directly from the digital recorder to Box at the earliest opportunity and deleted from the recording device, as the audio recording device does not have encryption functionality. Audio files of the interviews will be stored and deleted once transcription of the interview has been completed.

Please answer the following questions *only* if you have not completed a Data Management Plan for an external funder

8a. How will you share and preserve the data underpinning your publications for at least 10 years e.g. PURE?
Supporting data will be provided in an electronic format on the journal website, with unrestricted access post-publication. Data will also be deposited in Lancaster University's institutional data repository and made freely available with an appropriate data license. Lancaster University uses Pure as the data repository which will hold, manage, preserve and provide access to datasets produced by Lancaster University research.

8b. Are there any restrictions on sharing your data ?

Due to the small sample size, even after full anonymization there is a small risk that participants can be identified. Therefore, supporting data will only be shared on request with academic researchers. Access will be granted on a case by case basis by the Research Supervisor or Head of Department of the Faculty of Health and Medicine.

9. Consent

a. Will you take all necessary steps to obtain the voluntary and informed consent of the prospective participant(s) or, in the case of individual(s) not capable of giving informed consent, the permission of a legally authorised representative in accordance with applicable law? yes

b. Detail the procedure you will use for obtaining consent?

Consent to participate will be gained via the completion and signing of a study consent form. In the event of a telephone interview, consent will be gained verbally and recorded via voice recorder.

10. What discomfort (including psychological eg distressing or sensitive topics), inconvenience or danger could be caused by participation in the project? Please indicate plans to address these potential risks. State the timescales within which participants may withdraw from the study, noting your reasons.

Current literature suggests the people who have cancer show high prevalence rates of psychological distress (e.g. Zabora, BrintzenhofeSzoc, Curbow, Hooker, & Piantadosi, 2001). It is possible therefore, that sharing the story of their journey through cancer treatment has the potential to cause distress.

Participants will be informed and reminded that they can stop the interview at any time. The researcher, as a Trainee Clinical Psychologist, has developed skills in containing people in immediate distress as part of their training. However, no therapy will be take place between the researcher and participants. Participants will also be signposted to services if appropriate and contact details made available as part of the study debrief (see study information sheet).

Participants will be made aware in the consent form that they are free to withdraw at any time up until March 2017, as the analysis and write up will be completed and draft read by this point. Before this point the interviewee will be free to withdraw without giving reason or negative consequences.

Before the start of the interview, interviewees will be asked about their preference of action, should they become upset. This may include having break, rescheduling, or contacting someone for them.

Participants will be signposted to services if appropriate and contact details made available as part of the study debrief. Debriefing will take place at the end of the interview when the participant about their experience of the interview and given the opportunity to ask any questions. National support numbers will be provided. Confidentiality will be ensured, unless there is disclosure of information that suggests somebody is at risk of serious harm. In this case advice from my research supervisor will be sought. Participants will be made clear of this verbally and within the study information sheet.

11. What potential risks may exist for the researcher(s)? Please indicate plans to address such risks (for example, noting the support available to you; counselling considerations arising from the sensitive or distressing nature of the research/topic; details of the lone worker plan you will follow, and the steps you will take).

The Lancaster University's Lone Work guidance will form the basis of the plans to address field working risks. In particular Section 5 of the code of practise for work on campus and fieldwork and personal safety off campus will be followed when lone working. See pages 44-46 of http://www.lancaster.ac.uk/depts/safety/files/Fieldwork.pdf.

When interviewing off campus:-

1.Upon arrival at the premises the Researcher should phone a designated contact (course colleague or family member) from outside the premises to assure them they have arrived safely and that the phone is working. Contact should be maintained at specified time intervals. If the Researcher decides that the designated person is a household member or friend this would be agreed with the Supervisor, as it is the University who is responsible for ensuring the Researcher's safety.

2. An emergency plan should be developed for situations where contact is not maintained or return times are missed. This would be to contact the University department. The name and address of the person the researcher is scheduled to meet will be left in a sealed envelope with the designated contact, only to be opened in the event of an emergency and once contact is made with the department (Either by main department switchboard or out of hours mobile phone). If the department cannot be contacted the police should be contacted and their advice followed.

3. Researchers are given information from previous interviews where relevant.

4. If Researchers are concerned about a visit in advance then, they will arrange to be accompanied or to be phoned during the visit.

12. Whilst we do not generally expect direct benefits to participants as a result of this research, please state here any that result from completion of the study: There may be no direct benefit to participation in this study. However participation in the research may be a positive experience as the study may benefit others who face the cancer journey and health professionals working with this population.

13. Details of any incentives/payments (including out-of-pocket expenses) made to participants: Some travel expenses in terms of mileage may be required for any interview attendance. These are expected to be minimal as participants are likely to live in the vicinity of the interview venue, which is likely to be the place in which the interviewee's support group takes place, or within the participant's home. Travel costs up to the maximum value of £10 will be reimbursed by Lancaster University DClinPsy.

14. Confidentiality and Anonymity

a. Will you take the necessary steps to assure the anonymity of subjects, including in subsequent publications? yes

Please include details of how the confidentiality and anonymity of participants will be ensured, and the limits to confidentiality. Participants will be given the option of choosing a pseudonym, having a pseudonym assigned by the researcher, or retaining their own name, as retaining their own name which can prevent 'loss of ownership' (Grinyer, 2002). Participants who choose to retain their own name, will be reminded that this may make their interview data more identifiable and given the option to reconsider. If an inappropriate name is chosen, the participant will be informed that its use in the study write up may not be guaranteed and will be decided by the research supervisors. The option to generate an alternative name, in the event that the original pseudonym is not permitted, will be given. Transcription will be carried out by the researcher. References to individuals or organisations during the recording of the interviews will be anonymised during the transcription process. Confidentiality will be ensured, unless there is disclosure of information that suggests somebody is at risk of serious harm. In this case advice from my research supervisor will be sought. Participants will be made clear of this verbally and within the study information sheet.

15. If relevant, describe the involvement of your target participant group in the *design and conduct* of your research.

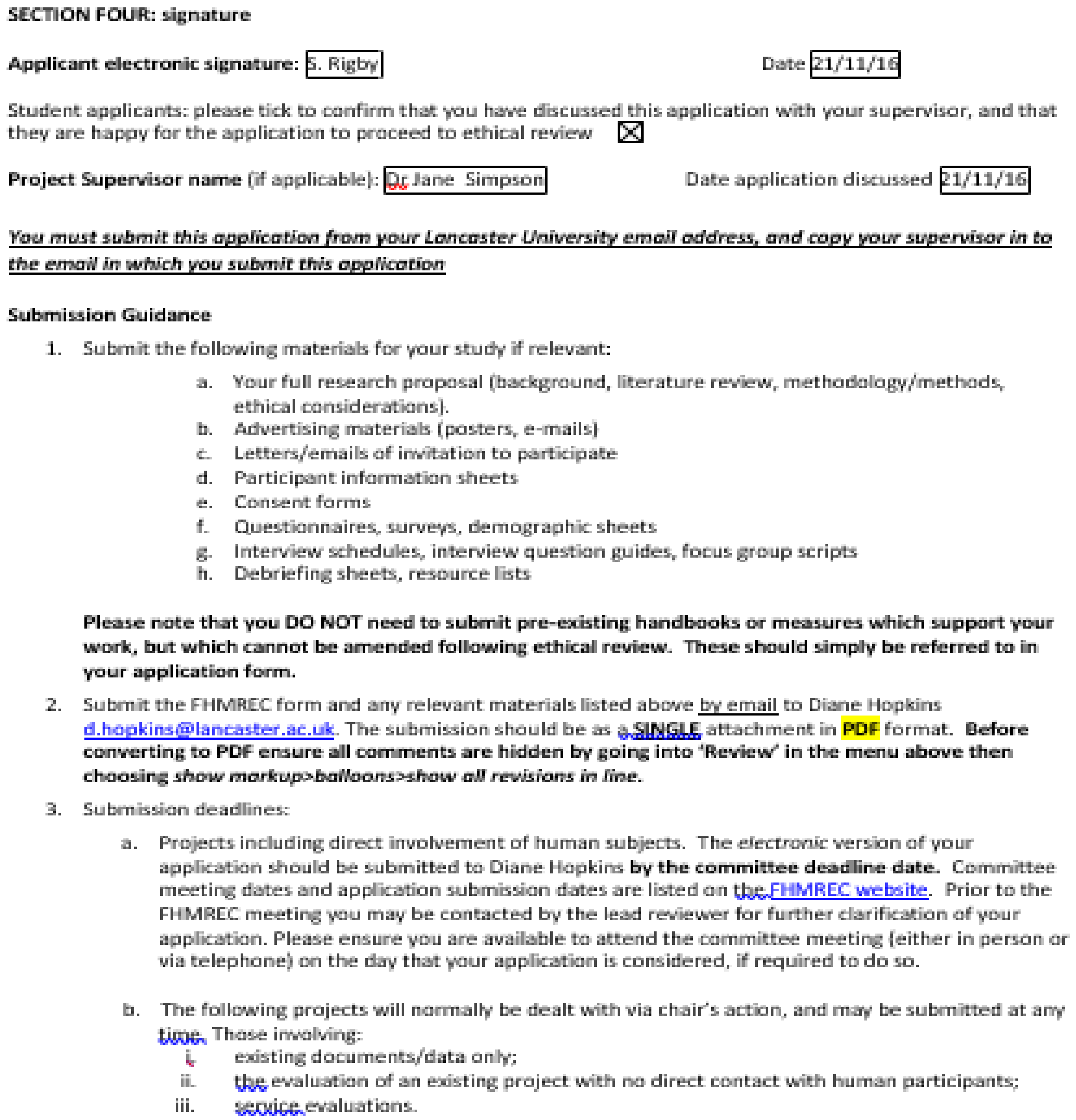
A service user, who currently meets the target cancer participation criteria, has provided feedback on the study materials. However, there has not been direct involvement from the target group in the design and conduct of the research.

16. What are the plans for dissemination of findings from the research? If you are a student, include here your thesis.

The initial mode of dissemination will be via Doctoral Thesis. The research team involved in this work and those examining it, will be privy to the results. The results of the research will be submitted for publication in an academic/professional journal and, as a result, may be published. A summary of the story will be made available for participants who would like these. Findings may also be presented at applicable conferences

17. What particular ethical considerations, not previously noted on this application, do you think there are in the proposed study? Are there any matters about which you wish to seek guidance from the FHMREC?

The participants may give negative comments on treatment they have received or an organisation that they have been recruited through. Although this is not expected, nor does it form the basis of the research, the breath of experiences that the participant may choose to cover as part of their own narrative and sense of self may include many and varied aspects of their cancer journey. Reassurance will be offered as to the neutrality of the interviewer, the usefulness of all parts the participant’s story related to the topic and that anonymity will be maintained.



SECTION FOUR: signature

Applicant electronic signature: S. Rigby Date 21/11/16

Student applicants: please tick to confirm that you have discussed this application with your supervisor, and that they are happy for the application to proceed to ethical review ☒

Project Supervisor name (if applicable): Dr Jane Simpson Date application discussed 21/11/16

You must submit this application from your Lancaster University email address, and copy your supervisor in to the email in which you submit this application

Submission Guidance

1. Submit the following materials for your study if relevant:
    a. Your full research proposal (background, literature review, methodology/methods, ethical considerations).
    b. Advertising materials (posters, e-mails)
    c. Letters/emails of invitation to participate
    d. Participant information sheets
    e. Consent forms
    f. Questionnaires, surveys, demographic sheets
    g. Interview schedules, interview question guides, focus group scripts
    h. Debriefing sheets, resource lists

    Please note that you DO NOT need to submit pre-existing handbooks or measures which support your work, but which cannot be amended following ethical review. These should simply be referred to in your application form.

2. Submit the FHMREC form and any relevant materials listed above by email to Diane Hopkins d.hopkins@lancaster.ac.uk. The submission should be as a SINGLE attachment in PDF format. **Before converting to PDF ensure all comments are hidden by going into 'Review' in the menu above then choosing *show markup>balloons>show all revisions in line.***
3. Submission deadlines:
    a. Projects including direct involvement of human subjects. The *electronic* version of your application should be submitted to Diane Hopkins **by the committee deadline date.** Committee meeting dates and application submission dates are listed on the FHMREC website. Prior to the FHMREC meeting you may be contacted by the lead reviewer for further clarification of your application. Please ensure you are available to attend the committee meeting (either in person or via telephone) on the day that your application is considered, if required to do so.

    b. The following projects will normally be dealt with via chair's action, and may be submitted at any time. Those involving:
        i. existing documents/data only;
        ii. the evaluation of an existing project with no direct contact with human participants;
        iii. service evaluations.

Thesis Research Protocol

Doctorate in Clinical Psychology

Title: The role of difficult emotions in the cancer treatment journey

Researcher: Selane Rigby

Research Supervisors: Dr. Jane Simpson (Lancaster University) and Dr. Philip Powell (University of Sheffield)

Date: 21st November 2016

Self-disgust as a psychological concept is difficult to define, although features unique to disgust can be used to distinguish self-disgust from other closely-related affective phenomena in the general population. However, theoretically self-disgust can be viewed as an emotional schema by which disgust is directed towards the self and, if enduring, can have negative consequences for a range of mental health and behavioural outcomes (Powell, Simpson, & Overton, 2014). Furthermore, due to the infancy of the concept of self-disgust, there is a dearth of literature exploring the role of disgust directed at oneself in people with long-term physical health conditions.

Much of the research on self-disgust to date is concentrated in mental health. For example, self-disgust has been hypothesized to function as an antecedent to the depressive experience and play a role in depression (Overton, Markland, Taggart, Bagshaw, & Simpson, 2008). However, self-disgust may also persist in the absence of depressive experience (Powell, Overton, & Simpson, 2014). Moreover, it is likely that physical aspects of oneself can activate self-disgust (Reynolds, McCambridge, & Consedine, 2015). Furthermore, physical symptoms of ill health, as well as the effects of treatment, have the potential to active the self-disgust schema, therefore in long-term physical health conditions these self-disgust elicitors can become commonplace and unavoidable (Reynolds, et al., 2015). Indeed, recent longitudinal research suggests that self-disgust may not only partially mediate links between dysfunctional thoughts and depressive symptoms but that disgust towards physical aspects of oneself have the potential to be a more important predictor than disgust towards behavioural aspects of the self (Powell, Simpson, & Overton, 2013).

One of the most prevalent physical health problems and a leading cause of death in United Kingdom is cancer. Although incidence of cancer is rising, mortality rates are falling due to advancements in detection and treatments (Office for National Statistics, 2015). However, as with other long-term health conditions, mental health can impact on how cancer patients respond to treatment, (e.g. DiMatteo, Lepper, & Croghan, 2000), decide on treatment, adhere to treatment protocols (e.g. Reynolds, Bissett, Porter, & Consedine, 2016) and duration of survival (e.g. Falagas et al., 2007). In particular, anxiety and depression feature most prominently in the literature, as prevalence rates among people with cancer are estimated to be at least double that of the general population (Hinz, et al., 2010).

Moreover, recent studies using quantitative methodology has found that self-disgust is a mediator of psychological distress in adults with cancer (Powell, Azlan, Simpson, & Overton, 2016; Azlan, Overton, Simpson, & Powell, 2016). The former study found that experiencing physical side-effects of cancer treatments, such as nausea, bowel and bladder problems, considered to be elicitors of core disgust responses, were indicative of increased psychological distress symptomology. Furthermore, the effect of core disgust side-effects on self-disgust were also moderated by one's underlying disgust propensity (Powell, et al., 2016). Disgust sensitivity in cancer populations has also been found to significantly predict depressive symptoms over and above matched controls (Azlan, et al., 2016). Moreover, self-directed disgust mediated the impact of core disgust side-effects on psychological adjustment to cancer treatment (Powell, et al., 2016), highlighting the relevance of self-disgust in relation to the cancer journey.

However, the theoretical story of how self-disgust develops and changes throughout the course of cancer treatment is as yet unexplored. Indeed, the experience of self-disgust over the course of any health condition has yet to be the subject of research investigation. Given the role of self-disgust in avoidance and/or protection, its potential impact on interactions with treatment and psychological wellbeing and therefore recovery are important to consider.

Furthermore, due to the rejection responses of oneself and schematic appraisal driven by self-disgust, it is likely that the rejection of others may also be anticipated, leading to social withdrawal in order to avoid the expected rejection from others. Therefore, it is suspected that self-disgust may be an important mechanism underpinning the social withdrawal common in adaption to long-term physical health conditions, including cancer (Reynolds, et al., 2015).

As self-disgust is a relatively new research topic, little guidance is available to clinicians working within long-term physical health conditions generally. Indeed although current theories of self-disgust highlight negative implications, such as avoidance, self-disgust as a protective mechanism is even less well understood in a physical health context. Moreover, given the original role of disgust in the protection from threats to health, physical health maybe a context in which self-disgust may also be beneficial, for example, in encouraging wound self-management and wound care treatment (Gaind, Clarke, & Butler, 2011).

Consequently, the primary aim of this study is to investigate the role of self-disgust, as a self-conscious emotion, throughout the course of cancer treatment. The evidence from personal narratives can highlight when the self-disgust is most prominent within the cancer treatment journey and, equally importantly when and how self-disgust becomes more dormant (in line with its conceptualisation as an emotion schema). Moreover, a greater understanding of the psychological trajectory of self-disgust in people who have had cancer will provide guidance to health care professionals working with this population. The specific research question for this study is: what are the narratives of self-disgust in individuals who have experienced treatment for cancer?

Method

Participants

Participants will be adult age (18 years or older) who have had a cancer diagnosis (any) but are no longer in active treatment (i.e. radiotherapy/chemotherapy). Information on participant demographics will be collected and will include age, gender, ethnicity, primary cancer diagnosis, type and duration of cancer treatment, age of onset and time elapsed since active treatment.

Inclusion Criteria.

1. Participants will be adults (18 years and above) at the time of interview. Although may have been younger at the time of treatment.
2. Participants will identify with having experienced self-disgust (from the study information sheet and/or study advertisement description) at some point throughout the course of their cancer journey/treatment.

Exclusion Criteria.

1. Participants cannot have a ‘watch and wait’ tumour diagnosis.
2. Participants will not be in active treatment (i.e. radiotherapy/chemotherapy) when they are interviewed but could be on less invasive treatments (e.g., hormone therapy with tamoxifen).
3. Non English speaking as this type of analysis (narrative) requires the speaker and interviewer/researcher to be fluent in the same language.

Sample

The intended number of participants will be up to 15 people in order to obtain enough data for chapters of the self-disgust story in cancer to emerge. This is in line with published research using narrative methods (e.g., Simpson, Heath & Wall, 2014).

An open approach to the sampling will be adopted initially. In the event that more than 15 expressions of interest are received, a purposive approach will be triggered. Purposely sampled participants will be selected based on variety of experiences and backgrounds, in an attempt to best represent a wide variety of perspectives.

Design

This is a qualitative study using narrative analysis to analyse data from one to one interviews involving up to 15 participants. The participants will be recruited via a study information sheet given to people who have expressed an interest in the project. Potential participants will have involvement/support from a regional cancer charity and identify themselves as having experienced self-disgust/self-conscious emotion, either during or after their cancer experience, prior to being interviewed from the definition given in the study information. Participants interested in taking part in the study will contact me to arrange an interview time and date. Data will be maintained by the researcher in order to ensure fidelity, validity and reflexivity.

Procedure

Recruitment.

Participants will self-identify as having experienced self-disgust prior to being interviewed from the definition contained in the participant information sheet and study advertisement. They will be recruited from the community and will have been treated for at least one form of cancer. Regional cancer charities and support groups such as xxxxxxxxxxxx will be contacted by the lead researcher using a university telephone or email account. The organisation will be provided with a participant information sheet if initial contact is via email, or forwarded via email after an expression of interest on telephone contact. Any other information they wish to review, i.e. ethical approval before promoting the study, will be sent via university email. If the organisation consents to advertising the study, all necessary materials will be sent. The promotion of the study by consenting organisations can be done via electronic media channels such as social media, website, email and online forums, as well as more traditional routes such as newsletters, word of mouth and notice boards. The advertisement and participant information sheet will contain the contact information of the researcher (university email and telephone) and will ask potential participants to contact the researcher directly.

Once contacted, the researcher will answer any questions potential participants may have about the study and, if agreeable with the participant, arrange a time and place for an interview to take place. Interviews will take place at participants' homes, a room on the university campus or a venue in the community, according to the participant's preference. The Lancaster University lone working guidance will be followed, with particular reference to Section 5 of the code of practise for work on campus and fieldwork and personal safety off campus. As a last resort, telephone interviews will be offered and arranged.

Consent.

Consent to participate will be gained via the completion and signing of a study consent form. In the event of a telephone interview, consent will be gained verbally and recorded via voice recorder.

Interview.

Given the nature of narrative analysis, in that it is interested in individuals' personal perspectives of their own story and sense of self by allowing space for the narrative to evolve, the interview will be mainly unstructured and will begin by asking the main question; an invitation for participants to talk about their experience of difficult or self-conscious emotions, throughout their cancer journey. However in order to maintain the focus of the research question, the researcher may ask questions to clarify a point, or to expand on an area of interest, from a neutral position. The interviews will be audio recorded and transcribed by the researcher. A transcript of their interview and summary of the story will be sent to consenting participants, once the study has been submitted for assessment.

Analysis.

Narrative analysis will be used to analyse the interview data. This type of analysis places emphasis on the interplay between self and context. The core element of this type of analysis is the uncovering of the self-construct, in particular how participants view themselves and how this view is shaped. Furthermore, it focuses on the process of shaping and the contributing factors (Weatherhead, 2011). This is a useful approach for answering the research question, in that is allows for in-depth exploration of the development of self-disgust as part of the view of self, throughout the cancer treatment journey.

Confidentially.

Participants will be given the option of choosing a pseudonym, having a pseudonym assigned by the researcher, or retaining their own name which can prevent 'loss of ownership' (Grinyer, 2002). References to individuals during the recording of the interviews will be anonymised during the transcription process. The interview recordings will be transported and stored securely. The recordings will be uploaded to Box at the earliest opportunity and deleted from the recording device.

Demographics will be collected from the recorded data and stored electronically in a password protected file on the Lancaster University server, Box. Any names and contact details will be stored on Box in a separate password protected file and deleted once the summary of findings have been delivered and the study assessed.

Audio files of the interviews will be stored and deleted once transcription of the interview has been completed. Scanned consent sheets and typed transcripts will be stored electronically on Box (Lancaster University server) for 10 years. A member of the research team will be responsible for deleting the files after this time has elapsed.

Potential to cause distress.

Current literature suggests the people who have cancer show high prevalence rates of psychological distress (e.g. Zabora, BrintzenhofeSzoc, Curbow, Hooker, & Piantadosi, 2001). It is possible therefore, that sharing the story of their journey through cancer treatment has the potential to cause distress.

Participants will be informed and reminded that they can stop the interview at any time. The researcher, as a trainee clinical psychologist, has developed skills in containing people in immediate distress as part of their training. However, no therapy will be take place between the researcher and participants. Participants will be signposted to services if appropriate and contact details made available as part of the study debrief.

Timescale

Ethics form complete – Sept 2016

Ethics Approval – November 2016

Data Collection – November 2016 – March 2017

Data Analysis & Write up – October 2016 – May 2017

References

Azlan, H. A., Overton, P. G., Simpson, J., & Powell, P. A. (2016). Differential disgust responding in people with cancer and implications for psychological wellbeing. *Psychology & Health*. doi: 10.1080/08870446.2016.1235165

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Sample advertisements

Participants Needed

Have you experienced difficult emotions about yourself during your cancer treatment journey?

As a result of the experience of being diagnosed and treated for cancer, some people can find that they experience difficult feelings about themselves - feelings such as guilt, shame or disgust.

If you have experienced these feelings, are not having active treatment, and are over 18 years old, I would love to hear your story.

For more information visit *insert link to PIS*. Or please contact me on:-

Selane Rigby Tel: xxxxxxxxxxxxx
Email: s.rigby1@lancaster.ac.uk

Trainee Clinical Psychologist
Faculty of Health and Medicine
(Division of Health Research)
Lancaster University
Lancaster
LA1 4YG

Website and Social Media:

Have you experienced difficult emotions about yourself during your cancer treatment journey?

As a result of the experience of being diagnosed and treated for cancer, some people can find that they experience difficult feelings about themselves - feelings such as guilt, shame or disgust.

If you have experienced these feelings, are not having active treatment, and are over 18 years old, I would love to hear your story.

For more information click here*insert organisation* page

Or please contact me on:

Selane Rigby Tel: xxxxxxxxxxxxx
Email: s.rigby1@lancaster.ac.uk

Trainee Clinical Psychologist
Faculty of Health and Medicine
(Division of Health Research)
Lancaster University
Lancaster
LA1 4YG

Twitter advert:
Have you experienced difficult emotions about yourself during your cancer treatment journey? Participants needed for a psychology study *insert organisation* page

Email invitation:-

PARTICIPANTS REQUIRED

Have you experienced difficult emotions about yourself during your cancer treatment journey?

As a result of the experience of being diagnosed and treated for cancer, some people can find that they experience difficult feelings about themselves - feelings such as guilt, shame or disgust.

If you have experienced these feelings, are not having active treatment, and are over 18 years old, I would love to hear your story.

For more information visit *insert link to PIS*.

Or please contact me on:-

Selane Rigby   Tel: xxxxxxxxxxxxx

Email: s.rigby1@lancaster.ac.uk

Trainee Clinical Psychologist
Faculty of Health and Medicine
(Division of Health Research)
Lancaster University
Lancaster
LA1 4YG

Consent Form

Study Title: "Understanding difficult emotions about yourself in the cancer treatment journey"

We are asking if you would like to take part in a research project in order to understand the role self-conscious emotions throughout the cancer journey from your own personal story.

Before you consent to participating in the study we ask that you read the participant information sheet and mark each box below with your initials if you agree. If you have any questions or queries before signing the consent form please speak to the principal investigator, Selane Rigby.

Please initial each statement

1. I confirm that I have read the information sheet and fully understand what is expected of me within this study ☐
2. I confirm that I have had the opportunity to ask any questions and to have them answered. ☐
3. I understand that my interview will be audio digitally recorded and then made into an anonymised written transcript. ☐
4. I understand that audio recordings will be kept until the research project has been examined. ☐
5. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐
6. I understand that once my data have been anonymised, incorporated into a themes and written up ready for submission, I will not be able to withdraw. ☐
7. I understand that the information from my interview will be pooled with other participants' responses, anonymised and may be published. ☐
8. I consent to anonymised quotations from my interview being used in reports and publications from the study. ☐
9. I understand that any information I give will remain strictly confidential and anonymous unless it is thought that there is a risk of harm to myself or others, in which case the principal investigator may need to share this information with her research supervisors. ☐
10. I consent to Lancaster University keeping written transcriptions of the interview for 10 years after the study has finished. ☐
11. I understand that the researcher will share and discuss data with their supervisors. ☐
12. I consent to take part in the above study.

Name of Participant__________________ **Signature**____________________ **Date** ___________

Name of Researcher __________________**Signature** ____________________**Date** ___________

Interview Schedule

Pre-interview

Gender: M/F

Age: ____________

Ethnicity ___________________________________

Primary cancer diagnosis:____

Type of cancer treatment:____

Duration of cancer treatment: ____

Age of onset:___________

Time elapsed since active treatment ______________________________________

The interview typically lasts for around 60 minutes, but will depend on the participant and their information sharing. There is no pressure to give information that you do not feel comfortable with. You can take breaks at any time during the interview and ask for the recording to be paused.

You may like to talk about friends, family, or professionals in your answers and if you do it would be helpful to talk about them in a way that prevents them from being identified.

Interview Questions

Would you like to tell me about how you felt about yourself, throughout your cancer journey?

Possible prompts – Can you tell me more about …….? How did these feelings impacted on …..? I would be interest to learn more about……. if you are ok to share more with me.

Debrief

That is the end of the interview questions. Is there anything that you would like to add that you've not had the opportunity to do so? (wait for response). Do you have any questions about the interview?

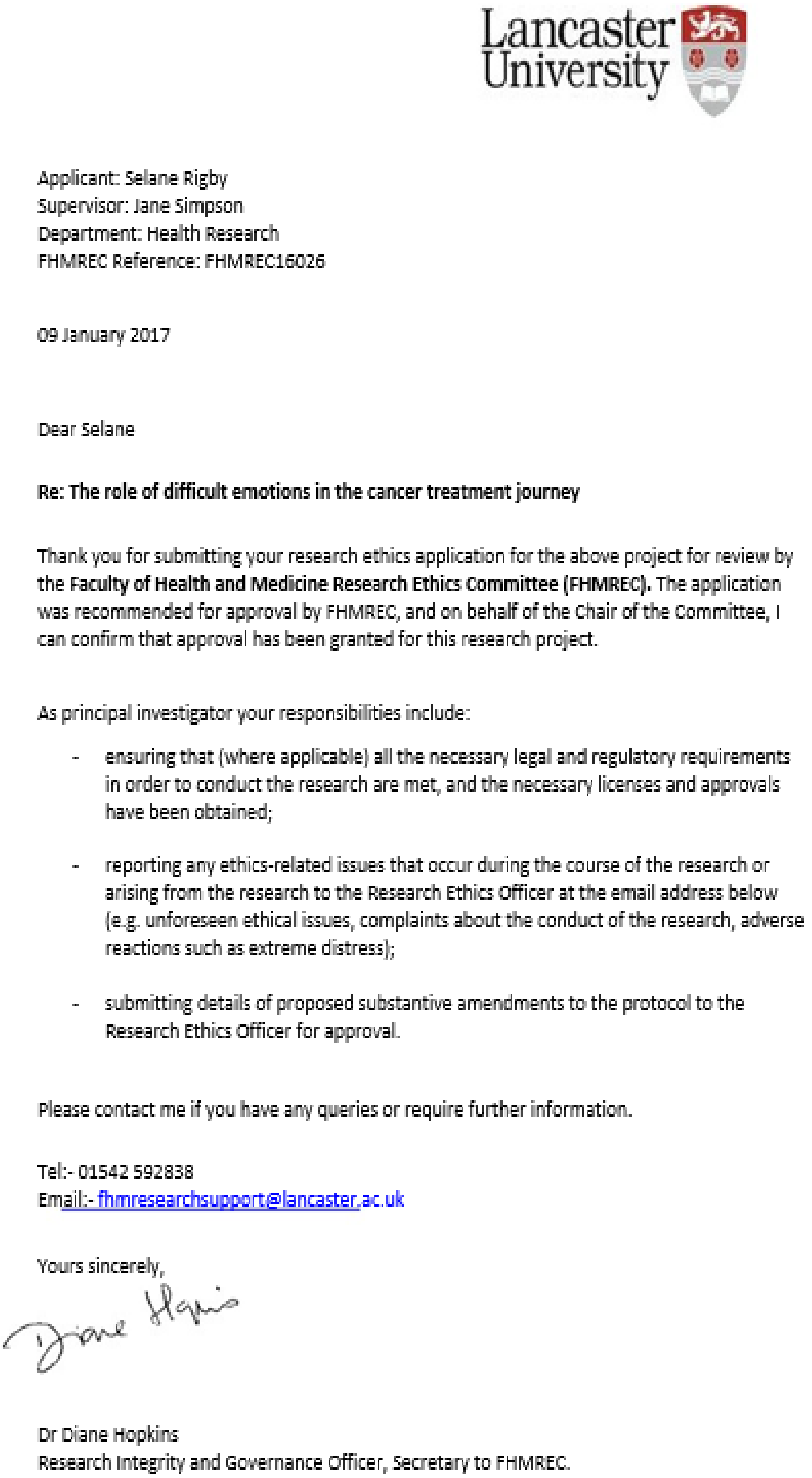
EMOTIONAL EXPERIENCES OF CANCER TREATMENT

How do you feel about having taken part in this interview?

Contact details for xxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxx and the mental health charity MIND are available on your participant information sheet. Would you like to be contacted in future with a summary of the overall research results? Y/N

If so, how would you like to be contacted? Telephone/email: ______________________________

Thank you for your time and taking part in this study.



Lancaster
University

Applicant: Selane Rigby
Supervisor: Jane Simpson
Department: Health Research
FHMREC Reference: FHMREC16026

09 January 2017

Dear Selane

Re: The role of difficult emotions in the cancer treatment journey

Thank you for submitting your research ethics application for the above project for review by the **Faculty of Health and Medicine Research Ethics Committee (FHMREC).** The application was recommended for approval by FHMREC, and on behalf of the Chair of the Committee, I can confirm that approval has been granted for this research project.

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;
- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer at the email address below (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);
- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact me if you have any queries or require further information.

Tel:- 01542 592838
Email:- fhmresearchsupport@lancaster.ac.uk

Yours sincerely,

Diane Hopkins

Dr Diane Hopkins
Research Integrity and Governance Officer, Secretary to FHMREC.