**“I would describe myself as a deformed troll”: Using Interpretative Phenomenological Analysis to explore body image struggles among palliative care patients.**

**Abstract**

**Background.** Illness adjustment is a widely studied area in the palliative care context. However, research focusing on how altered body image can affect men and women in palliative care is limited and unclear.

**Aim.** To explore the links between palliative care patients’ affected sense of self, altered body image and terminal illness adjustment.

**Design.** Semi-structured interviews were conducted, and the Interpretative Phenomenological Analysisapproach was used to analyse patients’ experiences.

**Setting/Participants.** English-speaking, adult palliative care outpatients were interviewed at a local community hospice in the United Kingdom. The mean age was 55 years (ranging from 35 – 65).

**Results.** Analysis of accounts indicated three superordinate themes: (I) ‘Not being me’: self-discrepancy, (II) Existing in the landscape of loss, (III) Living and thriving in the landscape of loss. The most disturbing issues, such as appearance-focused struggles and low body-confidence were stemming from participants’ frustration over their lack of control and their attachment to their former self-image.

**Conclusions.** The patients’ insights demonstrated that body image distress was prevalent amongst all respondents regardless of gender or diagnosis. A spiral model is described showing how discrepancy-based processing (i.e. ‘not being me’) and rigid attachment to former self, can have harmful consequences on palliative patients’ abilities to cope. In order to facilitate adjustment to a self-identity crisis resulting from a terminal diagnosis, it is necessary for professionals to recognise and address body image changes among palliative care outpatients.

**Keywords**

body image, self-concept, coping, adjustment, qualitative, palliative care

1. **What is already known about the topic?**
* Terminal illness may advance rapidly, impairing cognitive mechanisms and limiting the body’s function to perform identity relevant tasks.
* Bodily changes affect the self, yet body image changes are under-researched in palliative care patients.
* If changes affecting the self are not adequately addressed, it can result in diminished self-concept and worse psychological outcomes.
1. **What this paper adds?**
* Qualitative analysis of the links between self-discrepancy and terminal illness adjustment.
* Highlights that appearance-focused and personal identity struggles were among the key issues for both men and women.
* Describes how discrepancy-based processing (i.e. ‘not being me’) and rigid attachment to former self, can have harmful consequences on palliative patients’ abilities to cope.

**3. Implications for practice, theory or policy**

* When managing palliative care patients, professionals should recognise that body image changes are also critical features of patients’ affected sense of self.
* Health professionals should aim to heighten patients’ awareness to recognise and disengage from states of mind that can spiral to a more severe distress.
* Interventions should focus on addressing discrepancy-based processing and enhancing psychological flexibility by cultivating an accepting present-focus awareness of one’s feeling state.

**Introduction**

When cure may no longer be an option, quality of life becomes the main objective for the patient, family and service providers.1 Palliative patients suffer from physiological and psychological difficulties including threats to their sense of self.2-6 In adjusting to terminal illness, individuals have to overcome impairment to personal and social identities.7 Being a palliative care patient involves a constant awareness of the fragility of life, as patients try to arrange their lives to incorporate treatment and individual goals. Terminal illness is often depicted as a ‘turning point’, which can transform individuals’ lives in both negative and positive ways.7 Although these patients may not be cured they may experience ‘healing’, a sense of well-being that is derived from overcoming an aversive state to restore integrity.8 Positive aspects of long-term illness entail an expansion of personal boundaries by integrating past and future perceptions in a way that enhances the present life8 and the ability to derive benefits from adversity (i.e. post-traumatic growth).9 It has been suggested that post-traumatic growth may facilitate adjustment to disease, but it is less clear whether growth can be linked to decreased psychological distress.10 Furthermore, bodily changes after invasive treatments can lead to significant distress11 where a belief in self-efficacy, coping and work towards accepting a new image is undermined and patient morale may suffer and care needs increase.6 Historically in the UK, the larger proportion of palliative patients will have advanced cancer and the smaller proportions are those with end-stage organ failure and neurodegenerative diseases.12 Generally, terminally-ill patients in the UK are referred to hospices, which are places where specialist care and support are delivered. The majority of hospice care (~84%) is provided through community-based settings.13 All care is free of charge in UK hospices, and based on patients’ medical needs, a range of services are available from in-patient care to hospice day care. At the day care units, outpatients usually attend services one day per week, which may involve pain control, symptom relief, specialist nursing care and complementary therapies (e.g. physiotherapy).

It has been argued that within palliative care, many health professionals focus on physical rather than psychological symptoms.14 The support is often restricted to pharmacological interventions that aim to ameliorate negative consequences of the diagnosis such as anxiety and depression.15 There are a plethora of studies 16-25 that have focused on body image of individuals affected by cancer; however, to our knowledge only a few studies26-27 have investigated the issue of altered body image and adjustment among palliative care patients. This may indicate that body image issues in palliative care may be overlooked.

The processes from diagnosis to treatments and palliative care could be described as ‘embodied life events’ in which patients alter their social concept of the body and conclude what this means for their personal identity.16 Palliative patients’ identities can be a convoluted subject in relation to adjustment. One way to disentangle the interplay between self-concept, and patterns of helpful/unhelpful behaviours which facilitate adjustment, is by using exploratory constructivist qualitative research, focusing on the meanings attached to these issues by patients.28 Thus, this study is influenced by constructivism and is ontologically rooted in interpretivism, where a phenomenon and its meaning is conceptualised as being continuously altered through social interactions.29 Accordingly, the current study employed the Interpretative Phenomenological Analysis (IPA),30 which is deep-rooted in phenomenology and symbolic interactionism, and it seeks to understand the expression of human experience as it occurs within the social world. This study is novel in a sense that it used IPA to analyse a series of semi-structured interviews to explore how altered body image is constructed within the terminal illness experience.

**Methods**

*Participant Selection*

Consistent with IPA recommendations, 31 our aim was to find a fairly homogeneous sample with similar demographic/socio-economic state profiles, sharing the experience of being diagnosed with a terminal illness and receiving palliative care. In the context of long-term illness, personal and social factors that affect adjustment to illness are closely interrelated.10 Factors, such as class, race, ethnicity and age, play essential roles in illness adjustment. For instance, adjustment of an 80 year old man differs from that of a middle-aged man.32 To reduce unwanted variation in the current study, we aimed to recruit a younger adult population (between 18 and 65 years old) through a local day care hospice. Newly admitted patients (<4weeks) were excluded, as admission time can be anxiety provoking for some.

First, we purposively selected a larger volunteer sample of outpatients (N = 35) who were attending the day hospice and were equally eligible to be interviewed. From this purposive sample, 13 people were randomly assigned for the interviews. This was done to achieve the target sample and to reduce selection bias effects. IPA studies generally recruit small samples, as IPA aspires to construct a very detailed interpretative account of the interviews and to produce an in-depth analysis about perceptions and experiences.31 Therefore, a target sample of 10-13 participants was decided, depending on data saturation. Data saturation was defined by the richness of data, and as the point in data collection and analysis, when repetitive comments were observed and new information added little or no change.

*Data Collection*

Overall, 13 interviews were facilitated individually by a female Health Psychologist (first author) who had met the participants prior to the interviews. Participants were interviewed once for about 40 minutes over three days (13th, 20th, 27th July, 2016). The interviews took place at a local community hospice, in Central England. The interviews were conducted in a room within a hospice where confidentiality could be maintained and were recorded with a Dictaphone. Field notes were made following the interviews. All the recordings were stored securely on a computer. A list of topics offered a provisional structure to the interview and these were intended to be broad to allow participants to raise issues, which they felt were imperative. These topics were: (1) Describing thoughts and feelings about the body, (2) How illness has affected day-to-day activities, social life and sexual life, (3) What would help to cope better with changes?

*Analysis*

IPA analyses of semi-structured interview data were conducted, and the strategy was to move from the descriptive to the interpretative analysis.30 The focus was upon a ‘person-in-context’,33 how a specific individual in a specific circumstance understands his/her experience in the context of that individual’s ‘relatedness’ to the phenomena. The transcripts were studied in 3 main phases: (a) constructing exploratory summaries, (b) exploring linguistic aspects, and (c) engaging with the text interrogatively and conceptually.30 In terms of assessing validity, Yardley’s recommendations34 were followed and an ‘independent audit’ was carried out by a Senior Health Psychologist (2nd author). Verbatim excerpts from participants were used to support arguments being made30 and the consolidated criteria for reporting qualitative research (COREQ)35 were followed.

*Reflexivity*

 The authors acknowledge that their own beliefs, and interests in applications of phenomenological ideas to health psychology, and experiences about palliative care could have influenced the interpretation of the data. Whilst a relativist position was used with regards to the data collected, the analysis was underlined by both a relativist and realist position.

*Ethics*

Ethical approval was gained from [anonymised until published] Ethics Panel in May 2016. The guidelines recommended by the British Psychological Society36 were used to ensure ethical practice. All participants were given an information letter and consent sheet. At the end of each interview, participants were given a debrief sheet and were invited to reflect on their feelings or any concerns about the interview. The participants were also reminded of the opportunity to request additional information and to access the report, which would be developed from the study. To ensure anonymity of the participants, pseudonyms were used to identify respondents in the report.

**Results**

*Participant characteristics*

Thirteen participants were interviewed for the study and nobody declined. 54% of participants were female and the mean age was 55 years (ranging from 35 – 65), only four out of the 13 people reported receiving psychological support at the time of the interview.). Participants’ summary details are given in Table I.

Table 1 about here

*Themes*

Analysis of accounts indicated three superordinate themes: (I) ‘Not being me’: self-discrepancy; (II) Existing in the landscape of loss; (III) Living and thriving in the landscape of loss. These themes reflected on the processes that foster inflexible or flexible adjusting to a self-identity crisis resulting from a terminal diagnosis. Furthermore, the main themes consisted of interrelated subordinate themes (see Table 2) adding further depth in conceptualising the phenomenon.

Table 2 about here

*1. ‘Not being me’: Self-Discrepancy*

*The eroded self-image: “I would describe myself as a deformed troll”* All the participants experienced changes to their bodies and self. Body image dissatisfaction, feeling old and worn out in one’s own body were predominant occurrences.

If it wasn’t for the fact that my husband wasn’t as ill as he was...I would have to hide in a box rather than let him see me naked. Err...my legs have gone misshapen and are huge, and the skin and texture it’s like they are going...as if the pores of the skin are swollen and grown out and they are grown like warts. But they look like err, I can’t describe it in anything else, so it’s like blisters, but they look like warts dents have appeared within the legs as well. And to me it looks like a troll. So I would describe myself as a deformed troll. It’s horrible…. [Sandra, 57].

*Loss of body functionality.* All the participants had become less mobile and less confident in their bodies. This affected their abilities to work, drive, cook, and play or do certain house chores. In light of the reduced sense of self-sufficiency, they experienced an array of negative emotions (e.g. anger, frustration and sadness) that were closely connected with the experience of not being able to control or change this aspect of life.

Sometimes it gets me down when I can’t do things, I do feel wobbly every now and then. I don’t have a go at anybody else just with myself. I slap the bloody side, or I kick something, easy things that I used to be able to do and I can’t do them that does send me loopy. But I know I can do, but me body can’t. And I think ‘Oh I can do this, it’s easy!’ And I can’t do it now, and it does make you go mad. [Martin, 55].

*Gender identity struggles*. Women and men both noted that they struggled to maintain their old sense of gender identities. Whilst women felt less feminine and upset due to the appearance changes, men were experiencing conflicting reactions, such as suppressing feelings in order to uphold deep-rooted hegemonic masculinity norms.

I was dreading losing my hair but by the time I actually did I got used to the idea. It was something I dreaded but luckily I didn’t lose it at the first chemo treatment. I think you stop feeling as feminine. And stop trying to put make up and things on, I don’t feel girly anymore like I used to [Victoria, 64].

Also, participants noted that the changes in their bodies had a negative impact on their sexual life. Whilst women generally accepted this, for men the reduced sexual life was more of an issue.

I am concerned about my sexual life. I would love to improve it. I haven’t talked about it openly, and no one asked me about it or talked to me about what to expect after the treatments. Nothing at all. No, they haven’t been very good at all in that respect. I was definitely unprepared for it all. Definitely. But if they’ve told me I might would have refused the treatment. Because it destroyed my sex life. [Thomas, 35].

*Reduced social life*. Change of social self and reduced social life was also found across all the interviews and was associated with a sense of not fitting in, losing of friends, feeling insecure and vulnerable in one’s body and being dependent on family members and carers.

I think they perceive me differently. I mean I’ve lost friends and err... because I’ve slowed down so much I suppose I can’t keep up with them anymore. And I don’t know it just feels like as people just think ‘Oh God! Not going with Joanna, she is just too slow!’ I can’t talk to them. I get really tongue tied. I’ve got invited to a summer party, to Carole’s. This is one of my old friends I still see. Well, I don’t see much of her now. I can’t go. I can’t go out with people. I don’t feel comfortable [Joanna, 52].

*2. Existing in the landscape of loss*

 *“I try and block it out”* Accounts of loss illuminated some recurring patterns in people’s reactions that fostered reactive coping, inflexibility and limited capacity to deal with the losses. To address the felt sense of self-discrepancy participants acquired different forms of reactivity patterns. Although these aspects of self-management were considered as temporarily efficacious for surviving loss, they prevented participants from fully engaging with life. These strategies often resulted in a sense of numbness and reacting to events in a mechanical or anxious and angry way. Generally, when participants attempted to avoid being in contact with feelings, thoughts or other external experiences they were aware that this strategy only provided them a temporary solution and required lots of effort.

I look fat and worn out. The steroids made me have a big stomach and I never used to have one. And it bothers me, it affects how I see and how I feel about myself everyday. It upsets me. I don’t think about it if I can. I try and block it out with anything I can do. I watch a lot of films. I sing in my head quite a lot. [Thomas, 35].

 *”I do cover myself up”* Commonly, struggle is a sign of non-acceptance and a step toward effective coping is positive acceptance. The participants’ struggles with non-acceptance resulted in unhelpful ‘fixing’ behaviours, for instance, trying to hide perceived physical flaws.

I do cover myself up when I get out of the pool, actually. Which I never used to do. And friends say, you know ‘You don’t look that bad!’ but, you know I just feel, I don’t know, it’s just very, very depressing. And it does annoy me when people say, ‘Oh you look fine!’, because I know they are lying. They just saying to sort of cheer you up. The reality is that you’ve got to adjust to it and accept that you are not that person before the diagnosis, really [Keith, 54].

*3. Living and thriving in the landscape of loss.*

*Communal coping.* Restoration of the eroded self-confidence were related to finding ways in enhancing old, self-centred views to re-establish a self that has the capacity to grow, to be proactive, and foster psychological flexibility. Participants reported that they consider the day hospice as a safe space where they can share universal experiences and flourish socially, which in turn increases their sense of self-efficacy and positive emotional reactions to adversity.

At the moment my legs are big, but they aren’t as big as they have been...I don’t like it when, I feel like I’m on show, when my legs are huge... It makes me feel conscious and I try my best. But on the other hand, when you are amongst friends, which the people here have become, you don’t feel as conscious of yourself as such like when you are meeting with other people in the shop [Sandra, 57].

There was a general sense of gratefulness when participants talked about the unconditional support that they receive from family members, which aimed at further easing their hardships and the transitioning from lack of self-sufficiency to positive illness adjustment and an improved quality of life.

I lost my hair during the second course of treatments. But the consultant did say, ‘You are going to lose your hair.’ And I says, ‘Oh okay’. But it’s growing back a bit now. But I will lose it again, but that’s okay. I’m not bothered this time. I can live without hair, it doesn’t bother me, you know. Err...me Mum says to me ‘It doesn’t matter if you have hair or not Angela, it doesn’t does it?’ she says, ‘As long as we got you that’s all that matters!’. And that helped me. Family, they really have been amazing. I can’t fault them at all. All of them have been really good [Angela, 47].

**Discussion**

*Key findings*

The patients’ insights demonstrated that body image distress was prevalent amongst all respondents regardless of gender or diagnosis. Body image changes in terminal illness were shown affect the sense of self through three key themes. These themes illuminated different embodied self-experiences, such as, the primary experience of self-discrepancy, the experience of being in the landscape of loss, and finally, making the most out of the circumstances and thriving in the midst of loss. The most disturbing issues, such as appearance-focused struggles and low body-confidence were stemming from participants’ frustration over their lack of control and their attachment to their former self-image.

*What this study adds*

The present findings add to the body of knowledge on palliative care by demonstrating the links between patients’ affected sense of self and terminal illness adjustment. Discrepancy-based processing has been examined in various health-related contexts (e.g. chronic pain).37 A close representation, which is conceptualised based on the perceived difference between one’s ‘actual’ and ‘ideal’ self is ‘Self-Discrepancy Theory’.38 According to this, higher level of perceived incongruence between the ideal and the actual self will result in high-arousal negative cognitions, such as anxiety and distress. In the terminal illness context, self-discrepancy appears when patients perceive themselves as the present person who is not the person s/he wants to be (i.e. undesired self) and fall short to live up to their own ideas of former self (i.e. ideal self). In our study, such discrepancy-based processing triggered negative self-evaluations among the participants, such as body image dissatisfaction and low body-confidence. Regardless of gender, respondents reported disturbance in their appearance and confidence, which contributed to their gender identity, sexual and social life struggles. Some experienced body-related embarrassment, which generally occurs when a person sees him/herself as differing from the cultural standard, and it depends on the internalisation of this standard as a personal ideal.39 Terminal illness and its treatments caused various changes in participants’ bodies (e.g. hair loss, tooth loss, weight loss/gain, skin changes, lymphoedema, muscle atrophy, brittle nails and scars) and body image distress was stemming from participants’ frustration over lack of control and their attachment to their former self-image. As we stated earlier, the construct of body image has received attention in the oncology literature; however, the context of palliative care remains underexplored as the majority of studies have focused on women’s experiences and advanced breast cancer,26,40 and HIV.41-42 Our study showed that body image dissatisfaction was prevalent amongst almost all respondents regardless of gender or diagnosis. The appearance and gender-related identity struggles coupled with the loss of body functionalities left most participants with a feeling of not fitting in and vulnerable in their current social environment. Inevitably those whose middle-aged bodies are frail, who are carrying a terminal disease and can no longer socially identify with the contemporary ‘healthy and highly functional body’ ideal may struggle to accept their altered body image.43  In terms of dealing with self-discrepancy, participants employed various coping strategies and utilised external supports that were effective to some extent. Psychological inflexibility44 is based on Hayes’ inverse of the flexibility model and claims that it relates to an individual’s inability to be in contact with the present and modify behaviours according to the situation. Strategies that are ineffective for palliative patients have been described as coping mechanisms that do not ensure satisfactory quality of life or physical, emotional and social well-being.4 Within our sample, the strategies that promoted psychological inflexibility were considered ‘reactive’ in nature as they only temporarily attenuated the aversive feelings associated with losses and closely linked to a self-centred focus. Resigned or passive acceptance was also salient and considered as an ineffective response to undesirable events. Passive resignation has been associated with poor health outcomes, for instance, with decreased survival time in gay men with AIDS.45 On the other hand, positive acceptance refers to equanimity with momentary internal and external experiences.46 In psychological therapies, acceptance has an essential role in cognitive defusion, allowing aversive memories and experiences to be defined so that cognitive processing can take place and the individual can integrate these difficult experiences into her/his self-narrative or let them go.46 Conversely, resigned acceptance influences the trajectory of the emotional experience by maintaining emotional reactivity and the need for cognitive change.

*Implications for theory and practice*

Overall, the IPA themes highlighted that there is a close interrelationship between how patients progress and adjust in a dynamic and unique way. As Figure 1 shows below, the participants described how terminal illness and altered body image affects the sense of self and how adjustment may be influenced through various factors. Depending on external factors (e.g. available information and support) patients appear to oscillate between these states of reactive and proactive coping.

Figure 1 about here

**Figure 1.** Spiral Model of Terminal Illness Adjustment. Formulation of superordinate themes

The spiralling model illustrates that terminal patients’ sense of self is fragile and often oscillates between an old/ reactive and a new/ proactive sense of self, in a non-linear way. The subordinate themes (see Table 2) and the participants’ narratives illustrate how this unfolds. Discrepancy-based processing involving body image and body functionality is the starting point, which triggers a sense of self-discrepancy. However, this self-discrepancy also presents an opportunity for patients to adjust and restructure the self by expanding a self-focused attention into a wider, less self-centred viewpoint through relationships and daily activities. The model highlights that effective holistic support requires recognition of the individual psychological needs of each patient. In order to widen the capacity to cope, health professionals could help patients to identify what prevents them to fully engage with life and what strategies and interventions would help them to move forward towards personal growth. Building on the proposed model, when devising a psychological intervention for palliative patients, clinicians may consider including aspects of psychological flexibility to increase quality of life outcomes.

In our study, one factor that enhanced psychological flexibility was communal coping. The term communal coping refers to a social appraisal (e.g. people perceive a stressor as ‘our’ problem) as opposed to an individualistic appraisal (e.g. ‘my’ problem) and activates a process of collaborative coping.10 Participants’ assertions are in line with studies that have highlighted the importance of belonging and being socially connected during attending palliative day care.2, 47 Whilst a felt sense of ‘loss of self’ in chronic conditions can be exacerbated by social isolation,48-49 sharing the burdens of suffering with others enables patients to see the universal dimension of their illness (i.e. illness is impersonal, as opposed to personalising/ being attached to ‘why me?!’). It strengthens coping skills and increases self-sufficiency because they engage in what is most important to them.

*Strengths and limitations*

The strengths of this study are that it used interviews to explore in depth the issues faced surrounding body image within a group of people receiving palliative care. The interviews explored a sensitive topic within a vulnerable group who openly spoke about their difficult and often upsetting experiences. Another strength was the use of IPA to interpret and analyse the interviews, where guidelines and procedures were strictly adhered to. However, some limitations should be considered when interpreting the results. The respondents were exclusively middle-aged, White Caucasian, ambulatory, and mainly of middle class; therefore, the experiences with palliative care were potentially biased by a heterosexual, middle class worldview and restricted on individuals who had day hospice access and who were mobile. Additionally, our sample may not be representative of the general palliative outpatient population as those patients who attend day hospice may have different social preferences, expectations and support needs than those who do not attend or those who are older; thus, their experiences may differ. Finally, the majority of the participants interviewed in this study had a cancer diagnosis. It would be useful in future research to explore in further depth the experiences of those with other, non-cancer diagnoses.

**Conclusions**

A clear message from this study is that discrepancy-based processing (i.e. ‘not being me’) can trigger negative self-evaluations, such as body image dissatisfaction and low body-confidence among palliative patients. Rigid attachment to former self including body image can have harmful consequences on palliative patients’ behaviours. Grief has its own timing, defending against loss can be an intelligent and compassionate response as it gives patients the space and time to regain some energy, perspective and balance. However, if these ineffective strategies become ongoing attempts to control the experience, then personal growth cannot unfold, and it prevents the individual from fully engaging with life. Insights from participants elucidated the importance of organised emotional support. Managing body image distress is a vital part of psychological practice in the field of palliative care. As part of this, it is essential for health professionals to educate patients and their families about the processes, emphasising the normal and natural changes that may happen, and assist on how they can achieve the best possible quality of life.

**References**

1. Bovero A, Leombruni P, Miniotti M, Rocca G, Torta R. Spirituality, quality of life, psychological adjustment in terminal cancer patients in hospice. *EJC* 2016; 25(6):961-969.

2. Bradley S, Frizelle D, Johnson M. Coping with Terminal Illness: The Experience of Attending Specialist Palliative Day Care. *J* *Palliat Med* 2010; 13(10):1211-1218.

3. McPherson C, Wilson K, Murray M. Feeling like a burden: Exploring the perspectives of patients at the end of life. *Soc Sci Med* 2007; 64(2):417-427.

4. Sorato D, Osório F. Coping, psychopathology, and quality of life in cancer patients under palliative care. *Palliat Supp Care* 2015; 13(03):517-525.

5. Devins G, Beanlands H, Mandin H, Paul L. Psychosocial impact of illness intrusiveness moderated by self-concept and age in end-stage renal disease. *Health Psychol* 1997; 16(6):529-538.

6. Price A, Goodwin L, Rayner L, Shaw E, Hansford P, Sykes N et al. Illness perceptions, adjustment to illness and depression in a palliative care population. *BMJ Support Palliat Care* 2011; 1(Suppl\_1):A14-A14.

7. Bahti T. Coping Issues Among People Living With Advanced Cancer. *Semin Oncol Nurs* 2010; 26(3):175-182.

8. Coward D, Reed P. Self-Transcendence: A Resource for Healing at the End of Life. *Issues Ment Health Nurs.*1996; 17(3):275-288.

9. Tedeschi R, Calhoun L. Trauma & transformation: Growing in the aftermath of suffering. 1st ed. Thousand Oaks, CA: Sage; 1995.

10. Helgeson V, Zajdel M. Adjusting to Chronic Health Conditions. *Annu Rev Psychol* 2017; 68(1):545-571.

11. Fingeret M, Teo I, Epner D. Managing body image difficulties of adult cancer patients: Lessons from available research. *Cancer* 2013; 120(5):633–641.

12. Calanzani N, Higginson I, Gomes B. Current and future needs for hospice care: an evidence-based report. [Internet]. London: Commission into the Future of Hospice Care.; 2013 [cited 2016 Sep 25]. Available from: http://cdn.basw.co.uk/upload/basw\_103716-5.pdf

13. Caper K. Hospice care in the UK 2016 [Internet]. Hospice UK; 2016 [cited 2018 Aug 18]. Available from: https://www.hospiceuk.org/what-we-offer/publications?cat=d9545912-4ccd-608d-ad24-ff0000fd3330

14. Walshe C, Payne S, Luker K. Observing district nurses roles in palliative care: an understanding of aims and actions. *BMJ Support Palliat Care.*2012;2(Suppl 1):A2.3-A3.

15. Wilson K, Chochinov H, Graham Skirko M, Allard P, Chary S, Gagnon P et al. Depression and Anxiety Disorders in Palliative Cancer Care. *J. Pain Symptom Manage.*2007;33(2):118-129.

16. Ogle J, Ullstrup K. Breast Cancer as an Embodied Life Event: A Synthesis of Research and Theory and Directions for Intervention and Future Work. *Illn Crisis Loss* 2006; 14(3):223-244.

17. Chapple A, Ziebland S. Prostate cancer: embodied experience and perceptions of masculinity. *Soc Health Illn* 2002; 24(6):820-841.

18. Cohen M, Anderson R, Jensik K, Xiang Q, Pruszynski J, Walker A. Communication Between Breast Cancer Patients and Their Physicians About Breast-Related Body Image Issues. *Plas Surg Nurs* 2012; 32(3):101-105.

19. Dropkin M. Body Image and Quality of Life After Head and Neck Cancer Surgery. *Cancer Pract* 1999; 7(6):309-313.

20. Fingeret M, Nipomnick S, Crosby M, Reece G. Developing a theoretical framework to illustrate associations among patient satisfaction, body image and quality of life for women undergoing breast reconstruction. *Cancer Treat Rev* 2013; 39(6):673-681.

21. Fobair P, Stewart S, Chang S, D'Onofrio C, Banks P, Bloom J. Body image and sexual problems in young women with breast cancer. *Psychooncology* 2006; 15(7):579-594.

22. Harrington J, Jones E, Badger T. Body Image Perceptions in Men With Prostate Cancer. *Oncol Nurs Forum* 2009; 36(2):167-172.

23. Miller M. Identity and prostate cancer: Comments on a messy life. *J Gay Lesbian Ment Health* 2005; 9(1):119-129.

24. Rhoten B, Murphy B, Ridner S. Body image in patients with head and neck cancer: A review of the literature. *Oral Oncol* 2013; 49(8):753-760.

25. White C. Body image dimensions and cancer: a heuristic cognitive behavioural model. *Psychooncology* 2000; 9(3):183-192.

26. Fingeret M, Teo I, DeSnyder S. Body image struggles and breast cancer care: an under-recognized and undertreated issue with important implications for all patients. *Breast Cancer Manag* 2014; 3(3):251-260.

27. Stene G, Helbostad J, Amundsen T, Sørhaug S, Hjelde H, Kaasa S et al. Changes in skeletal muscle mass during palliative chemotherapy in patients with advanced lung cancer. *Acta Oncol* 2014; 54(3):340-348.

28. Forrester M. Doing qualitative research in psychology. 1st ed. Los Angeles: Sage; 2010.

29. Bryman A. Social Research Methods - 5th Edition. Oxford: Oxford University Press; 2015.

30. Smith J, Flowers P, Larkin M. Interpretative Phenomenological Analysis. 1st ed. London: Sage; 2009.

31. Smith J, Osborn M. Interpretative Phenomenological Analysis. In: Smith J, ed. Qualitative Psychology. A Practical Guide to Research Methods. London: SAGE Publications; 2015. p. 25-52.

32. Vas S, Forshaw M, Grogan S. Men's experiences of middle-age: an interpretative phenomenological analysis. *NORMA* 2016; 11(2):71-88.

33. Larkin M, Watts S, Clifton E. Giving voice and making sense in interpretative phenomenological analysis. *Qual Res Psychol* 2006; 3(2):102-120.

34. Yardley L. Dilemmas in qualitative health research. *Psychol Health* 2000; 15(2):215-228.

35. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care* 2007; 19(6):349-357.

36. British Psychological Society. Ethics & standards | BPS [Internet]. *Bps.org.uk.* 2014 [cited 2016 Apr 24];Available from: http://www.bps.org.uk/what-we-do/bps/ethics-standards/ethics-standards

37. Kwok S, Chan E, Chen P, Lo B. The ‘‘self’’ in pain: the role of psychological inflexibility in chronic pain adjustment. *J Behav Med* 2016; 39:908–915.

38. Higgins E. Self-discrepancy: A theory relating self and affect. *Psychological Rev* 1987; 94(3):319-340.

39. Bessenoff G, Snow D. Absorbing Society’s Influence: Body Image Self-Discrepancy and Internalized Shame. *Sex Roles* 2006; 54(9-10):727-731.

40. Brunet J, Sabiston C, Burke S. Surviving breast cancer: Women's experiences with their changed bodies. *Body Image* 2013; 10(3):344-351.

41. Callander D, Senn C. Examining the Role of Relationships, Body Image, Closeness to HIV/AIDS, and HIV Optimism in the Sexual Risks of Young Men Who Have Sex With Men. *J HIV AIDS Soc Serv* 2013; 12(2):205-223.

42. Huang J, Harrity S, Lee D, Becerra K, Santos R, Mathews W. Body image in women with HIV: a cross-sectional evaluation. *AIDS Res Ther* 2006; 3:17.

43. Grogan S. Body image. Understanding Body Dissatisfaction in Men, Women and Children. New York: Routledge; 2008.

44. Hayes S, Luoma J, Bond F, Masuda A, Lillis J. Acceptance and Commitment Therapy: Model, processes and outcomes. *Beh Res Ther* 2006; 44(1):1-25.

45. Reed G, Kemeny M, Taylor S, Wang H, et al. Realistic acceptance as a predictor of decreased survival time in gay men with AIDS. *Health Psychol* 1994; 13(4):299-307.

46. Lindsay E, Creswell J. Mechanisms of mindfulness training: Monitor and Acceptance Theory (MAT). *Clinical Psychol Rev* 2017; 51:48-59.

47. Walshe C, Roberts D, Appleton L, Calman L, Large P, Lloyd-Williams M et al. Coping Well with Advanced Cancer: A Serial Qualitative Interview Study with Patients and Family Carers. *PLOS ONE.*2017;12(1):e0169071.

48. Charmaz K. Loss of self: a fundamental form of suffering in the chronically ill. *Sociol Health Illn* 1983; 5(2):168-195.

49. Kinmond K, McGee P, Gough S, Ashford R. ‘Loss of self’: a psychosocial study of the quality of life of adults with diabetic foot ulceration. *J Tissue Viability* 2003; 13(1):6-16.

**Additional files**

**Table 1**. **Participants’ characteristics**

|  |  |  |
| --- | --- | --- |
|  | **Participants** | n = 13 |
|  | **Diagnosis** Advanced lung cancer | 2 |
|  |  Kidney cancer | 1 |
|  |  Multiple Myeloma and plasma cell leukaemia | 1 |
|  |  High grade brain tumour | 1 |
|  |  Advanced cervical cancer | 1 |
|  |  Advanced colon cancer | 1 |
|  |  Advanced liver cancer | 1 |
|  |  Advanced prostate cancer | 1 |
|  |  Advanced breast cancer | 1 |
|  |  Heart failure  | 1 |
|  |  Mesothelioma | 1 |
|  |  Advanced motor neuron disease**Age (years)** | 1 |
|  |  Mean age (SD) | 55 (7.88) |
|  |  Range | 35 – 65 |
|  | **Gender** Female | 7 |
|  |  Male**Marital Status** | 6 |
|  |  Married | 6 |
|  |  Single | 3 |
|  |  In civil partnership | 2 |
|  |  Divorced**Time since diagnosis (in years)** | 2 |
|  |  Mean (SD) | 4.13 (2.26) |
|  |  Median, range  | 4; 0.74-9 |
|  | **Receiving palliative treatments at time of interview** | 12 |
|  |  Chemotherapy  | 8 |
|  |  Radiotherapy | 4 |
|  |  Hormone Therapy | 2 |
|  |  Steroids | 5 |
|  |  Subcutaneous lymphatic drainage | 1 |
|  | **Underwent appearance-altering surgery** | 7 |
|  |  Surgery to remove cancer | 7 |
|  |  Colostomy | 2 |
|  |  Ileostomy | 1 |
|  |  Reconstruction surgery**Receiving psychological support at time of interview** | 1 |
|  |  Counselling at the local hospice | 4  |
|  |  |  |

**Table 2.** List of IPA themes

**1. ‘NOT BEING ME’: SELF-DISCREPANCY**

*1.1. The eroded self: “I would describe myself as a deformed troll”*

* Perceived accelerated ageing
* Loss of former self-image
* Body image dissatisfaction (maintained by aversion, polarised view, and self-criticism)

*1.2. Loss of body functionality*

* Reduced mobility
* Loss of body confidence and self-sufficiency

*1.3. Gender identity struggles*

* Loss of masculine/ female identity
* Diminished sexual life

*1.4. Reduced social Life*

* Not fitting in
* Increased sense of vulnerability
* Loss of friendships
1. **EXISTING IN THE LANDSCAPE OF LOSS**

*2.1.”I try and block it out”*

* + Dealing with losses by avoidance (e.g. thought suppression)
	+ Rumination and negative interpretations
	+ Resigned, partial, or passive acceptance

*2.2. ”I do cover myself up”*

* + Ineffective fixing behaviours
	+ Behavioural avoidance (e.g. distraction)
1. **LIVING AND THRIVING IN THE LANDSCAPE OF LOSS**

 *3.1. Communal coping*

* Hospice as a safe space to share universal experiences
* Practical support
* Structured emotional support and encouragement of emotional expressivity
* Family members’ unconditional support

**Figure 1.** Spiral Model. Formulation of superordinate themes

****

**Acknowledgments**

The authors wish to express their sincere gratitude to patients, health professionals and hospice staff members who have helped and participated in this project, either through assisting in the recruitment of patients or participating in the interviews.

**Funding**

This article presents independent research and has not been funded.

**Declaration of conflicting interest**

The authors declared no potential conflict of interest with respect to this article.

ORCID ID:  https://orcid.org/0000-0002-2262-6587