

Doctorate in Clinical Psychology

Cancer Survivorship, Identity and Meaning-Making

Part 1: Literature Review

Cancer Survivorship and Identity: A Review of the Research Literature

Part 2: Empirical Paper

Identity and Meaning Making in the Post-Treatment Phase for Cancer: An
Interpretative Phenomenological Analysis

Submitted by Sarah Jane Masson, to the University of Exeter
as a thesis for the degree of Doctor of Clinical Psychology, May 2014.

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Abbreviations

CASP - Critical Appraisal Skills Programme

DOH – Department of Health

EPHPP - Effective Public Health Practice Project

IPA – Interpretative Phenomenological Analysis

TVCRN CRP - Thames Valley Cancer Research Network Consumer Research Partnership

DOCTORATE IN CLINICAL PSYCHOLOGY

Literature Review

**Cancer Survivorship and Identity: A Review of the Research
Literature.**

Sarah Masson

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The author certifies that all material in this thesis which is not my own work has been identified and that no material has previously been submitted and approved for the award of a degree by this or any other University.

Abstract

Purpose

Cancer is a stressful life event that challenges self-identity. Several studies have considered cancer's impact upon patients' identity post-treatment. This review aims to consolidate their findings to understand what is known about cancer's impact upon identity in the post-treatment phase.

Methods

PsycINFO, Web of Knowledge and PubMed databases were searched using specific key words, and references of included articles were also searched for articles that met inclusion criteria.

Results

The findings of the twenty-eight studies included in this review were disparate. Identity roles affected by cancer were 'healthy', 'sexual', 'masculine/feminine', 'independent', 'occupational' and 'coherence'. Participants adopted roles of 'cancer patient' and in many cases 'survivor'. The importance of being more than a 'cancer patient' was emphasised. Participants described processes by which a coherent identity was reconstructed; these included relinquishing, redefining and renegotiating roles, to incorporate their cancer experiences.

Conclusions

Evidence suggests that specific cancers affect specific personal identity roles, resulting in the reconstruction of a global identity. The review identifies a lack of research evidence regarding cancer's impact upon global identity post-treatment and how patients successfully reconstruct self-identity.

Keywords

Cancer, Oncology, Identity, Self, Survivorship

Introduction

In England more than one million people have a diagnosis of cancer. This number is expected to rise to over three million by 2030 (Department of Health [DoH], 2010). One third of patients have unmet needs post-treatment, including psychological distress and concerns about recurrence (Armes et al., 2009). Psychological issues post-treatment include anxiety, depression, isolation, and negative impacts on self-image and self-identity (DoH, 2010). This review aims to clarify what is known about cancer's impact on self-identity.

The terms "identity" and "self-identity" have been widely used in various contexts and conceptualised in a variety of ways. General consensus is that identity is experienced at three levels: social, personal and ego (Cote & Levine, 2002). Social identity is the individual's position in a social structure, consisting of cultural factors and social roles. Personal identity consists of personal agency, biological dispositions and more idiosyncratic identity roles formed from prescriptive social identity roles, based on life history. Ego identity is the coherent, subjective sense of continuity. Erikson's (1968, 1980) work on identity formation has influenced the majority of contemporary formulations of identity in both psychology and sociology (Cote & Levine, 2002). Erikson (1968, 1980) posited that identity forms when all self-representations are integrated, and through the accumulated confidence that others will recognise what one deems one's self to be. This results in a subjective sense of continuity across social situations and over time. A coherent identity provides a sense of direction and ease in one's own body, the basis of successful adult development and psychological well-being (Erikson, 1968, 1980). Being able to accurately appraise, interpret and predict experiences, gives rise to a sense of the world as stable and coherent (Brennan, 2001). Individuals generate ideas of their

possible future selves that strengthen their sense of meaning and purpose (Markus & Nurius, 1986).

Continuous reconstruction of identity (Greenwald, 1980) and self-narratives (Mathieson & Stam, 1995) occur to incorporate new information and maintain coherence, giving meaning to the past- and present-self, as well as daily interactions. New experiences predicted by identity strengthen identity. However, unpredicted experiences create cognitive dissonance, conflict between the mental representation and reality, causing psychological distress (Festinger, 1957). Humans inherently try to reduce dissonance to regain internal consistency, resulting primarily in a drive to incorporate the experience into their identity or, alternatively, alter their identity to allow for the experience (Bosma & Kunnen, 2001). Disruption to identity coherence can cause an identity crisis, as the previous identity is no longer suitable and a more coherent identity has not yet been established (Cote & Levine, 2002). This results in a split self-image, confusion, a lack of engagement with social roles, instability in one's character and behaviour (Cote & Levine, 2002) and a sense of meaninglessness (Yalom, 1980). Cancer consists of numerous novel experiences that are likely to disrupt identity (Brennan, 2001).

Objectives

This review summarises existing research evidence, with the aim of understanding the potential impact of cancer upon an individual's identity post-treatment and to identify how to support any on-going psychological need once physical treatment is complete. This review identifies areas for further research, with the aim of informing the development of interventions for this population.

Methods

Eligibility Criteria

Focus. Studies focusing on the identity of individuals with cancer were included.

Population. Studies of individuals with a diagnosis of cancer, in the post-treatment phase (no longer receiving active treatment) and aged 18 or over were included. Only adult studies were included as identity findings in adolescents and children are likely to be confounded by interruptions to normal identity development.

Exclusion criteria. Studies including terminally ill patients were excluded as the experiences of these patients may be confounded by factors specific to the palliative phase.

Information Sources

Databases searched comprised PsycINFO (1986-2014) accessed through OVID, PubMed (1969-2014) and Web of Knowledge (1983-2014).

Search Strategy

The search strategy consisted of an online search of published peer-reviewed articles from 1969 to February 25th 2014. The title search terms were 'cancer', 'identity' and 'identities'.¹ The reference lists of all included studies were hand searched. Only studies published in English were included.

¹ See Figure 1 for specific filters used in each database: Flow chart of information through the different phases of the review.

Study Selection

The titles of all articles were searched, then the abstracts and finally the paper itself. At each stage studies were rejected if they did not meet the eligibility criteria.

Quality Appraisal

Quantitative studies were appraised using the Effective Public Health Practice Project's (EPHPP) (1998) Quality Assessment Tool for Quantitative Studies.² Qualitative studies were appraised using the Critical Appraisal Skills Programme's (CASP) (2006) quality appraisal tool.³ Areas considered when appraising study quality included: research design; sampling method; data collection; analysis; value of the research; and overall assessment of the study.

Data Collection Process

Data were independently extracted by the author. Any mention of specific identity roles impacted upon by cancer was extracted. Extracts were grouped by the relevant identity role.

Results

Study Selection

For a detailed description of study selection, see Figure 1. One hundred and forty two studies were identified in the database search. Twenty-eight met the eligibility criteria, of which three were excluded. Three additional studies

² See Appendix A: The EPHPP (2006) appraisal tool.

³ See Appendix B: The CASP (2006) appraisal tool.

were identified by searching the references of included articles. The full text was available and quality appraised for all twenty-eight of the eligible studies.

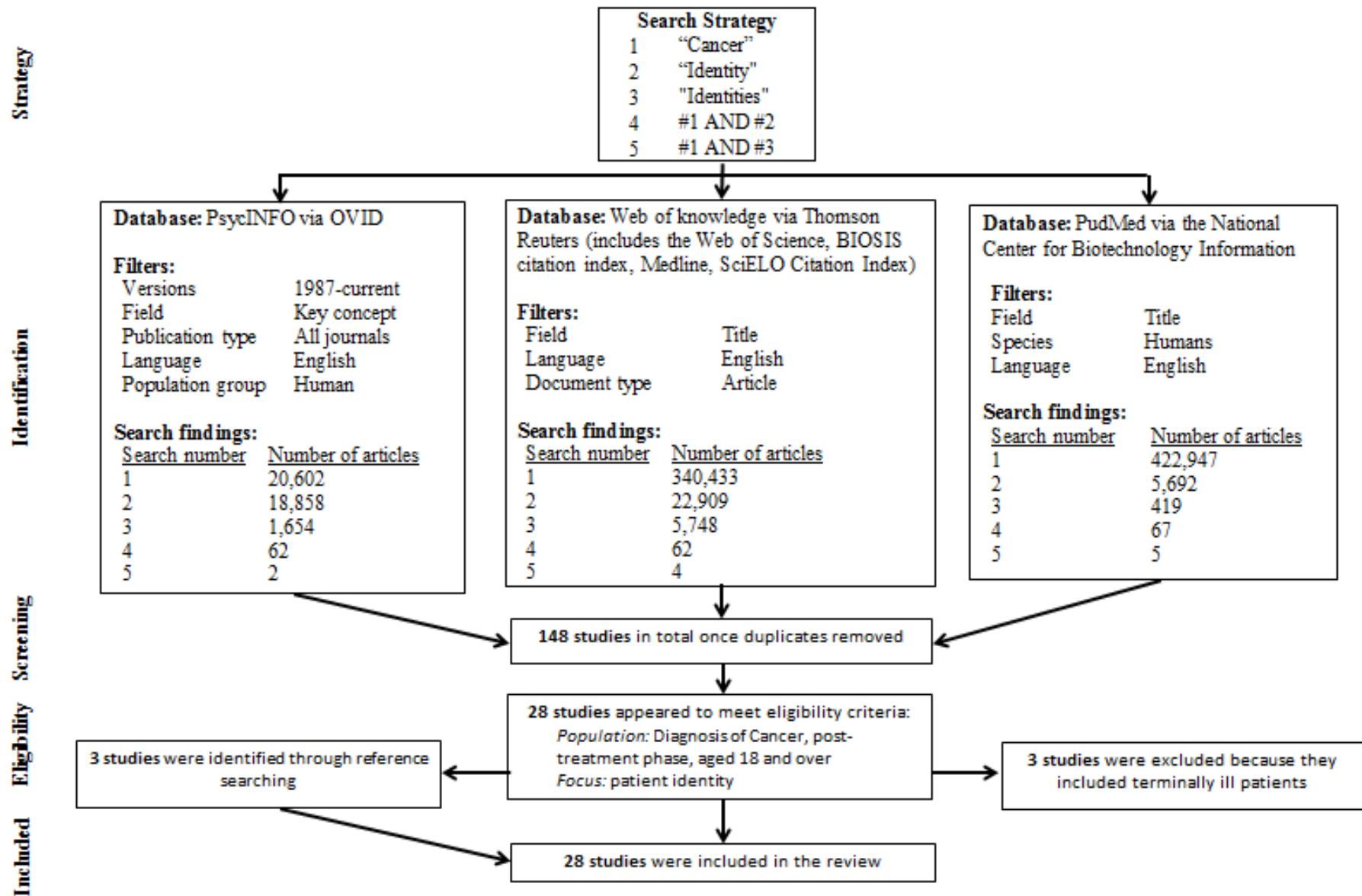


Fig. 1 Flow of information through the different phases of the review

Synthesis of Results

The majority of studies were focused on the experiences of people with breast, prostate or gynaecological cancers; there was little or no evidence regarding other cancer sites or more general commonalities across cancer sites. Five quantitative and twenty-three qualitative eligible studies were identified and quality appraised. For ease of reading, references for studies for key themes are not included in the text but can be found in Appendix C.

Quantitative studies. All five quantitative studies were rated 'weak', using the EPHPP quality appraisal criteria (1998) and had low response rates.⁴ Specific role identities investigated were 'survivor', 'masculine' and 'self-concept'. The identity measures provided categorical descriptions only, providing little insight into what meaning participants gave to these identity labels or how cancer impacted on these identity roles.

Salokari and colleagues (1986) found that some individuals with breast cancer felt self-conscious about their bodies; with some feeling their bodies had become alien to them. Zaider and colleagues' (2012) study of masculine identity reported that approximately one-third of men reported moderate or severe loss of masculinity, which correlated with sexual functioning concerns. Three studies explored survivor identity (Bellizzi & Blank, 2007; Chambers et al., 2012; Park, Zlateva, & Blank, 2009). The findings from these studies suggest that the most common survivor identities adopted in the survivorship phase were 'survivor' and 'someone who has had cancer'.⁵ However, Park and colleagues (2009) found that participants identified with multiple labels, each related to specific

⁴ See Appendix C: A summary of the quality appraisal of five quantitative studies included in the review, using the EPHPP tool (2006)

⁵ See Table 1.

psychological functioning, cancer appraisals, coping, and cancer-related activities. These findings suggest that the survivor concept is complex and requires further investigation.

Qualitative studies. Of the twenty three qualitative studies, one (4%) was rated 'excellent', using the CASP quality appraisal criteria (2006). Of the remaining studies, sixteen (70%) were rated 'good', five (22%) were rated 'borderline' and one (4%) was rated as 'poor'. Thematic synthesis was used to amalgamate the findings of the qualitative studies. Ways in which cancer had impacted upon participants' personal identity roles were extracted and tabulated, enabling the identification of key themes shown in Table 2.

Table 1
Survivor identity findings

<u>First author and year</u>	<u>Question asked</u>	<u>Response option</u>	<u>Survivors</u>	<u>Someone who has had cancer</u>	<u>Victim</u>	<u>Patient</u>	<u>Cancer conquerors</u>	<u>Non-responders</u>	<u>Other</u>
Bellizzi et al. 2007	When you think about yourself in relation to your prostate cancer, which adjective or phrase best describes you: a patient, a victim, someone who has had prostate cancer, cancer survivor or cancer conqueror?"	One that best describes self in relation to cancer	26%	57%	1%	9%	6%	2%	n/a
Chambers et al. 2012	How you would describe yourself in relation to your bowel cancer: a cancer patient; a cancer victim; a person who has had (or has) cancer; a cancer survivor; or other	One that describes self in relation to cancer	55%	39%	1%	1%	n/a	3%	0%
Park et al. 2009*	"When you think about yourself in relation to your cancer, how much does each of these phrases describe you?" 1) a victim of cancer, 2) a cancer patient, 3) a person who has had cancer, 4) a survivor	Each rated from 1 (not at all) to 5 (very much).	83%*	81%*	18%*	58%*	n/a	0%	n/a

* % is of participants who endorsed the label at least 'somewhat' or more

Table 2

Table of identity themes from the 25 qualitative studies

<u>Theme</u>	<u>Specific findings</u>	<u>Number of studies</u>
Healthy		15
	<i>Loss of healthy identity</i>	9
	<i>Unable to eat properly</i>	4
	<i>Changed sexual functioning</i>	6
	<i>Loss of fertility</i>	4
	<i>Change in appearance</i>	7
	<i>Different from others</i>	4
	<i>Expected recovery</i>	2
	<i>Prioritised healthy identity</i>	7
	<i>Vulnerable</i>	5
Cancer patient		5
	<i>Felt like just a cancer patient</i>	2
	<i>Not just a cancer patient</i>	3
Survivor		8
	<i>Survivor identity</i>	3
	<i>Normal identity</i>	5
	<i>Peer-support</i>	2
Sexuality		12
	<i>Loss of fertility and attractiveness</i>	6
	<i>Sexual functioning</i>	8
Masculinity and Femininity	<i>Sexual minority status</i>	2
		10
	<i>Sexual functioning</i>	6
	<i>Loss of fertility</i>	3
	<i>Incontinence</i>	1
	<i>Inability to provide for others</i>	1
	<i>Inability to care for others</i>	2
	<i>Appearance</i>	5
	<i>Loss of femininity/masculinity</i>	3
	<i>Sexual minority status</i>	2
<i>Redefined</i>	4	
Independent and caregiver identities versus a dependent identity		9
	<i>Independence</i>	3
	<i>Caregiver</i>	4
	<i>Family role</i>	4
	<i>Reclaiming roles</i>	4
	<i>Redefine</i>	1
Occupation		9
Coherence		15

Healthy. Many participants' healthy identities were threatened by cancer. Participants saw themselves as no longer healthy or functioning 'normally', instead becoming sickly, fatigued, pained, damaged and/or weak. These

changes altered how participants saw themselves, as well as their confidence in their physicality. This was perpetuated by constant reminders of cancer, such as changes in daily activities (e.g. eating), and physical changes (e.g. altered sexual functioning, loss of fertility and altered appearance), often due to scarring and treatment side-effects. Feeling isolated, detached, conspicuous, and not the same as peers also impacted upon participants' identity. This appeared to increase dissonance between current and previous functioning, as well as the functioning of others. The expectation of others that participants would return to their previous 'healthy' selves after treatment appeared to exacerbate the dissonance between how the participant felt they should be and how they actually felt.

For many participants, cancer emphasised the importance of being 'healthy'. However, some participants' also felt physically vulnerable to recurrence, preventing a full return to a 'healthy' identity.

Cancer patient. Some participants felt their identity was solely 'a cancer patient' during treatment and found it hard to reclaim a wider sense of identity post-treatment. Some participants emphasised their identity was more than just 'a cancer patient' and highlighted the importance of others acknowledging this.

Survivor. Several studies explored survivor identity, a label adopted by many participants. However, the way in which this was done varied. Kaiser (2008) found that some embraced the dominant meaning of having beaten cancer, adopting an exaggerated new cultural identity using slogans and symbols from various survivor 'networks'. Others renegotiated the survivor label, for example seeing cancer as an on-going war, doing their best to fight and survive battles, or adopting a more general survivor identity, surviving various life experiences not just cancer. For some participants, being a survivor

was linked with a positive outlook; others were only able to adopt a survivor identity once their treatment had been successful, or when their symptoms or the treatment effects had gone (Deimling, Bowman, & Wagner, 2007). Some participants adopted a survivor identity after engaging in a challenge-based peer-support experience, such as a sponsored motorbike-ride. This gave them greater strength in everyday life and some experienced personal growth (Morris, Campbell, Dwyer, Dunn, & Chambers, 2011).

Some participants distanced themselves from a survivor identity. Reasons for this were varied: not being close enough to death to be a survivor; not feeling they had survived due to fear of recurrence; feeling they were more than just a label; having other cultural explanations for their experience; feeling it ignored larger factors, such as the causes of cancer (Kaiser, 2008); or, not wanting others to wrongly see them as a 'victim' (Morris et al., 2011). In Kaiser's (2008) study, breast cancer survivors over the age of 65 did not adopt a survivor identity. Some were not aware of this label and others did not think it was relevant. Instead, they viewed their experiences as part of the aging process.

Participants described trying to live a 'normal' identity, despite scars, ongoing side-effects and symptoms. Some participants highlighted the importance of connecting with other survivors via support groups which provided reassurance, inspiration, hope, non-defensive relating and normalised feelings (Clarke, McCorry, & Dempster, 2011). However, attending survivor groups reminded some participants of their vulnerability, especially when members died (Clarke et al., 2011). Matuschka (Petersen & Matuschka, 2004) became an activist, contributing to a greater cause.

Sexuality. Loss of fertility and perceived reductions in attractiveness threatened participants' sexual identities, as did changes in sexual functioning: loss of regular intercourse (Klaeson & Bertero, 2008); limited ability to be sexual (Becvar, 1996); loss of interest in sex (Arrington, 2003; Beckmann, Johansen, Richardt, & Blichert-Toft, 1983); extant, or expected, functional problems (Komatsu et al., 2014; Tindle, Denver, & Lilley, 2009); and erectile dysfunction (Bokhour, Powel, & Clark, 2007; Miller, 2005). For some participants, these changes led to reduced confidence in their sexuality, which impacted on their relationships (Tindle et al., 2009) and sexual functioning (Klaeson & Bertero, 2008). Some participants redefined what it meant to be sexual, for example, focusing on obtaining trust and closeness through hugs and being held (Arrington, 2003; Klaeson & Bertero, 2008) or 'pleasing' partners in ways that did not require erections (Arrington, 2003; Maliski, Rivera, Connor, Lopez, & Litwin, 2008). Other participants downplayed the importance of a sex-life, prioritising being 'healthy' (Arrington, 2003; Komatsu et al., 2014), or used humour to cope with changes in physical functioning (Bokhour et al., 2007). For some participants cancer emphasised the importance of their sex-life, choosing to postpone treatment that might risk their sexual functioning (Arrington, 2003).

Two studies explored the experiences of women with a sexual minority status, including lesbians, bisexuals, and women who have a woman partner. Boehmer and White (2012) found that participants de-emphasised the importance of sexual minority status in relation to experiences of survivorship. Sinding, Barnoff, and Grassau (2004) found that participants felt health care professionals had ignored, dismissed or not engaged meaningfully with their lesbian identity, impacting negatively on their cancer care and support group engagement.

Masculinity and femininity. Participants' masculine/feminine identities were threatened by treatment side-effects, such as altered sexual functioning, loss of fertility, incontinence, inability to work and provide for their family, inability to care for others, and changes in appearance. Some participants experienced complete loss of gender identity, not knowing how to act and having to reclaim this role. Klaeson and Bertero (2008) observed that female participants felt 'odd' and marginalised as women. Some described feeling they had become their mothers and normalised their experiences by seeking information from their mothers about menopausal experiences. Matuschka (Petersen & Matuschka, 2004) reported that her identity didn't change but the reactions of others to her as a woman did. This led her to change how she expressed her femininity behaviourally, "being a one breasted woman disguised as a two-breasted woman" (p. 510). In studies exploring the experiences of women of sexual minority status, participants felt unacknowledged as women during their treatment (Sinding et al., 2004). The primacy of being a woman was highlighted and their survivorship experiences were predominantly related to this identity role (Boehmer & White, 2012).

Some participants redefined their feminine/masculine identity roles: being a man involves more than sex (Maliski et al., 2008); being a woman is not about appearance (Tindle et al., 2009); a shifted focus from motherhood to wider womanhood (Komatsu et al., 2014); becoming a 'good man' who is a provider, good husband, a competent professional and provides for his family; or, adopting the identity of a 'sixties guy' who is liberated, a lover, husband and able to see his impotence as humorous (Bokhour et al., 2007).

Independent and caregiver identities versus a dependent identity. Many participants reported that cancer threatened their independence,

caregiver and family identity roles. They reported needing support through the cancer journey which made them feel more dependent. Some participants experienced 'being like a baby' during treatment (Arrington, 2003; Maliski et al., 2008). Becvar (1996) no longer felt able to care for and help others as she had before. Changes of role within the family and role reversal were also experienced (Arrington, 2003; Clarke et al., 2011; Little, Paul, Jordens, & Sayers, 2002). Some participants came to appreciate the need to look after their own needs, becoming self-nurturing (Becvar, 1996; Morris et al., 2011; Shapiro, Angus, & Davis, 1997). A greater appreciation of the family role was also mentioned (Bokhour et al., 2007). Some participants highlighted the importance of reclaiming their caring, family and/or independent roles post-treatment (Clarke et al., 2011; Tindle et al., 2009). Some did this by helping others with cancer (Becvar, 1996; Little et al., 2002) and others by redefining their family role (Maliski et al., 2008).

Occupation. Continuing some pre-cancer activities or responsibilities appeared to help promote participants' positive self-appraisals and self-esteem (Clarke et al., 2011; Shapiro et al., 1997). Matuschka (Petersen & Matuschka, 2004) commented that working, contributing to a cause, seemed important in helping maintain her identity and preventing her from reflecting on the fact that she had cancer. Inability to engage with professional or caring activities resulted in a loss of self-worth and self-esteem (Clarke et al., 2011; McCorry, Dempster, Clarke, & Doyle, 2009). Not being able to do things they could do before disrupted the coherence of some participants' identities, for some this led to a sense of alienation (Little et al., 2002) and for others it threatened their masculinity (Maliski et al., 2008). However some participants, faced with the inability to work and uncertainty about returning to work, found a new way to

understand themselves. Some did this by adopting a new philosophy and disconnecting from their past self (Shapiro et al., 1997), some found a new focus and worked on adopting a positive outlook (McCorry et al., 2009), and others made changes at work which allowed them to fully be who they wanted to be (Carpenter, Brockopp, & Andrykowski, 1999). One participant even framed his experience in terms of his professional identity as an Engineer, construing his problem as mechanical which helped him manage cancer-related challenges (Bokhour et al., 2007). However, work role was not an important part of all participants' identities (Miller, 2005).

Coherence. Many participants experienced a loss of coherence in their identity, needing to renegotiate their global identity. Shapiro and colleagues (1997) identified three narratives related to adjusting to cancer treatment: 'rebirth', the formation of a new self, separate from the pre-cancer self; 'turning point', becoming more in line with who they were rather than being different; and, 'back to normal', being fundamentally the same unchanged person. In contrast, Carpenter and colleagues (1999) found the extent to which participants' identities altered, and/or their sense of coherence was restored, varied. Participants fell into three groups. 1) 'Positive transformation': brought on by increased self-awareness in the face of mortality, leading to changes in the self and relevant aspects of their lives, and increasing self-esteem and well-being. 2) 'Minimal transformation': the intensity with which these participants faced mortality was less than for those who experienced a positive transformation, resulting in increased self-awareness and either acceptance, or reinforcement of their current self, but with less desire to change and the downplaying of any changes. 3) 'Feeling stuck': in which facing mortality led to a desire to change but participants felt unclear about what changes should be

made, and lacked courage and support, resulting in low self-acceptance, self-esteem and well-being. Bokhour and colleagues (2007) found participants relied on previously valued identity roles to reconstitute themselves. Manderson and Stirling (2007) found reconstruction of the lost breast enabled participants with mastectomies to feel 'whole' again.

The expectations of others also impacted on participants' ability to feel they could be the person they saw themselves to be. Some participants felt they were not allowed to be themselves, instead they were expected to be happy and able to carry on (Klaeson & Bertero, 2008). Others changed how they expressed their identity behaviourally in response to others' expectations (Petersen & Matuschka, 2004).

Discussion

Summary of Evidence

Research evidence regarding cancer's impact on identity post-treatment was reviewed. For the majority of participants, their healthy identity was threatened and many had adopted a cancer patient identity. Some felt labelled by the patient identity, stressing that their sense of identity was more complex and multi-faceted. Many, but not all, participants in the post-treatment phase adopted a survivor identity, although the meaning of this identity varied. It seemed that some participants found themselves in a paradox between being a survivor and a cancer patient, having survived yet fearing recurrence. Participants' independent, occupational, caregiver and family identity roles were often threatened by treatment side-effects, resulting in dependence and an inability to perform usual activities, such as caring for others and working. It was important for participants to resume pre-cancer activities as fully as possible,

although when previous abilities were lost, some participants were able to redefine the relevant identity roles. Cancer symptoms, treatment and side-effects impacted upon gender and sexual identities, requiring participants to redefine or deprioritise these identity roles. For many participants, their global, coherent sense of identity was disrupted.

The evidence indicates that an individual's global self-identity needs to be re-established in the post-treatment phase. This occurred by relinquishing, renegotiating or reaffirming identity roles, reconstructing a coherent identity that incorporated the individual's cancer experiences. When participants were unable to do this, they were left feeling different and alienated and experienced low self-esteem and well-being. This highlights an area of on-going need in this population.

The importance of the responses of others and engaging in certain activities in re-establishing and validating identity roles and coherence were highlighted by participants. These findings suggest that research exploring interpersonal and social factors pertinent to identity in the post-treatment phase would be beneficial.

There is evidence that cancer impacts upon patient identity post-treatment. To date the majority of research has focused on specific cancer sites and specific identity roles. Further research into a wider variety of primary cancers is warranted, in order to gain a broader understanding of cancer's impact on identity post-treatment. This will provide a better understanding of the needs of this large population and more informed support for those who experience on-going difficulties. Participants commented on the importance of being more than just a label, emphasising the importance of healthcare professionals gaining

better insight into the nuances of patients' experiences of identity roles and identity coherence post-treatment.

Limitations

This review focused on papers with 'identity' as a keyword. However, relevant studies may have been missed if identity was not listed as a keyword. Identity is a multi-faceted concept; many different keywords may have been used to represent findings regarding identity, such as self-concept, masculinity, femininity and sexuality. In an attempt to identify pertinent papers potentially missed in the initial search, references lists of eligible studies were searched. However, it is possible that this review under-represents the findings regarding cancer's impact on identity post-treatment.

An additional point worth considering is that this review has included both quantitative and qualitative methods drawing from multiple theoretical and methodological traditions, conceptualising identity in a variety of ways. This has made comparison of studies more complex but provided a more comprehensive overview of the evidence to date.

Conclusions

It is clear that, to better support those who have ongoing difficulties, further research is needed to understand the full extent of cancer's impact upon identity in the post-treatment phase and factors intrinsic to the successful reconstruction of a coherent identity.

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Appendices

Appendix A: The EPHPP (2006) Appraisal Tool



EFFECTIVE PUBLIC HEALTH PRACTICE PROJECT (EPHPP)

Ref ID: _____
Author: _____
Year: _____
Reviewer: _____

QUALITY ASSESSMENT TOOL FOR QUANTITATIVE STUDIES

COMPONENT RATINGS

A) SELECTION BIAS

(Q1) Are the individuals selected to participate in the study likely to be representative of the target population?

- 1 Very likely
- 2 Somewhat likely
- 3 Not likely
- 4 Can't tell

(Q2) What percentage of selected individuals agreed to participate?

- 1 80 - 100% agreement
- 2 60 - 79% agreement
- 3 less than 60% agreement
- 4 Not applicable
- 5 Can't tell

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

B) STUDY DESIGN

Indicate the study design

- 1 Randomized controlled trial
- 2 Controlled clinical trial
- 3 Cohort analytic (two group pre + post)
- 4 Case-control
- 5 Cohort (one group pre + post (before and after))
- 6 Interrupted time series
- 7 Other specify _____
- 8 Can't tell

Was the study described as randomized? If NO, go to Component C.

No Yes

If Yes, was the method of randomization described? (See dictionary)

No Yes

If Yes, was the method appropriate? (See dictionary)

No Yes

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

C) CONFOUNDERS

(Q1) Were there important differences between groups prior to the intervention?

- 1 Yes
- 2 No
- 3 Can't tell

The following are examples of confounders:

- 1 Race
- 2 Sex
- 3 Marital status/family
- 4 Age
- 5 SES (income or class)
- 6 Education
- 7 Health status
- 8 Pre-intervention score on outcome measure

(Q2) If yes, indicate the percentage of relevant confounders that were controlled (either in the design (e.g. stratification, matching) or analysis)?

- 1 80 – 100%
- 2 60 – 79%
- 3 Less than 60%
- 4 Can't Tell

RATE THIS SECTION See dictionary	STRONG 1	MODERATE 2	WEAK 3
--------------------------------------------	--------------------	----------------------	------------------

D) BLINDING

(Q1) Was (were) the outcome assessor(s) aware of the intervention or exposure status of participants?

- 1 Yes
- 2 No
- 3 Can't tell

(Q2) Were the study participants aware of the research question?

- 1 Yes
- 2 No
- 3 Can't tell

RATE THIS SECTION See dictionary	STRONG 1	MODERATE 2	WEAK 3
--------------------------------------------	--------------------	----------------------	------------------

E) DATA COLLECTION METHODS

(Q1) Were data collection tools shown to be valid?

- 1 Yes
- 2 No
- 3 Can't tell

(Q2) Were data collection tools shown to be reliable?

- 1 Yes
- 2 No
- 3 Can't tell

RATE THIS SECTION See dictionary	STRONG 1	MODERATE 2	WEAK 3
--------------------------------------------	--------------------	----------------------	------------------

F) WITHDRAWALS AND DROP-OUTS**(Q1) Were withdrawals and drop-outs reported in terms of numbers and/or reasons per group?**

- 1 Yes
- 2 No
- 3 Can't tell

(Q2) Indicate the percentage of participants completing the study. (If the percentage differs by groups, record the lowest).

- 1 80 -100%
- 2 60 - 79%
- 3 less than 60%
- 4 Can't tell

RATE THIS SECTION See dictionary	STRONG 1	MODERATE 2	WEAK 3
--------------------------------------------	--------------------	----------------------	------------------

G) INTERVENTION INTEGRITY**(Q1) What percentage of participants received the allocated intervention or exposure of interest?**

- 1 80 -100%
- 2 60 - 79%
- 3 less than 60%
- 4 Can't tell

(Q2) Was the consistency of the intervention measured?

- 1 Yes
- 2 No
- 3 Can't tell

(Q3) Is it likely that subjects received an unintended intervention (contamination or co-intervention) that may influence the results?

- 4 Yes
- 5 No
- 6 Can't tell

H) ANALYSES**(Q1) Indicate the unit of allocation (circle one)**

community organization/institution practice/office individual

(Q2) Indicate the unit of analysis (circle one)

community organization/institution practice/office individual

(Q3) Are the statistical methods appropriate for the study design?

- 1 Yes
- 2 No
- 3 Can't tell

(Q4) Is the analysis performed by intervention allocation status (i.e. intention to treat) rather than the actual intervention received?

- 1 Yes
- 2 No
- 3 Can't tell

GLOBAL RATING

COMPONENT RATINGS

Please transcribe the information from the gray boxes on pages 1-4 onto this page.

A	SELECTION BIAS	RATE THIS SECTION See dictionary	STRONG 1	MODERATE 2	WEAK 3
B	STUDY DESIGN	RATE THIS SECTION See dictionary	STRONG 1	MODERATE 2	WEAK 3
C	CONFOUNDERS	RATE THIS SECTION See dictionary	STRONG 1	MODERATE 2	WEAK 3
D	BLINDING	RATE THIS SECTION See dictionary	STRONG 1	MODERATE 2	WEAK 3
E	DATA COLLECTION METHODS	RATE THIS SECTION See dictionary	STRONG 1	MODERATE 2	WEAK 3
F	WITHDRAWALS AND DROPOUTS	RATE THIS SECTION See dictionary	STRONG 1	MODERATE 2	WEAK 3

GLOBAL RATING FOR THIS PAPER (circle one):

- 1 STRONG (four STRONG ratings with no WEAK ratings)
- 2 MODERATE (less than four STRONG ratings and one WEAK rating)
- 3 WEAK (two or more WEAK ratings)

With both reviewers discussing the ratings:

Is there a discrepancy between the two reviewers with respect to the component (A-F) ratings?

- No Yes

If yes, indicate the reason for the discrepancy

- 1 Oversight
- 2 Differences in interpretation of criteria
- 3 Differences in interpretation of study

Final decision of both reviewers (circle one):

- 1 STRONG
- 2 MODERATE
- 3 WEAK

Appendix B: The CASP (2006) Appraisal Tool

Quality appraisal sheet.	
<i>Paper name</i>	
Aims Is there a clear statement of the aims of the research? <i>(What was the goal of the research was, why it is important, it's relevance)</i> Is a qualitative methodology appropriate for the authors' stated aims? <i>(if the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants)</i>	Yes / No Comments: Yes / No Comments:
Is a theoretical perspective explicit? Y/N	
Research Design Was the research design appropriate to address the aims of the research? <i>If the researcher has justified the research design (e.g. have they discussed how they decided which methods to use?)</i>	Comments:
Sampling Was the recruitment strategy appropriate to the aims of the research? <i>Explained how the participants were selected.</i> <i>Explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study.</i> <i>Discussions around recruitment e.g. why some people chose not to take part</i>	
Data collection Were the data collected in a way that addressed the research issue? <i>Setting for data collection was justified</i> – <i>if it is clear how data were collected (e.g. focus group, semi-structured interview etc.)</i> – <i>if the researcher has justified the methods chosen – if the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews were conducted, did they used a topic guide?)</i> – <i>if methods were modified during the study. If so, has the researcher explained how and why?</i> – <i>if the form of data is clear (e.g. tape recordings, video material, notes etc.)</i> – <i>if the researcher has discussed saturation of data</i>	
Reflexivity Consider whether it is clear: – <i>if the researcher critically examined their own role, potential bias and influence during:</i> – <i>formulation of research questions</i> – <i>data collection, including sample recruitment and choice of location</i> – <i>how the researcher responded to events during the study and whether they considered the implications of any changes in the research design</i>	

<p>Ethical Issues Have ethical issues been taken into consideration? - <i>if there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained</i> – <i>if the researcher has discussed issues raised by the study (e. g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)</i> – <i>if approval has been sought from the ethics committee</i></p>	
<p>Analysis Was the data analysis sufficiently rigorous? Consider: – <i>if there is an in-depth description of the analysis process</i> – <i>if thematic analysis is used. If so, is it clear how the categories/themes were derived from the data?</i> – <i>whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process</i> – <i>if sufficient data are presented to support the findings</i> – <i>to what extent contradictory data are taken into account</i> – <i>whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation</i></p>	
<p>Findings Is there a clear statement of findings? Consider: – <i>if the findings are explicit</i> – <i>if there is adequate discussion of the evidence both for and against the researcher’s arguments</i> – <i>if the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst.)</i> – <i>if the findings are discussed in relation to the original research questions</i></p>	
<p>Value of the research How valuable is the research? Consider: – <i>if the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature?)</i> – <i>if they identify new areas where research is necessary</i> – <i>if the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used</i></p>	
<p>Overall assessment of the study 1= excellent, 2= good, 3= borderline, 4 = poor.</p>	
<p>Comments</p>	

Appendix C: A Summary of the Quality Appraisal of the Five Quantitative Studies Included in the Review, Using the EPHPP Tool (2006)

First author and year	Cancer type	Identity Focus	Study design	Quantitative Measures	Sample	Country	Selection bias	Study Design	Confounders	Blinding	Data Collection methods	Withdrawals and Dropouts	Intervention Integrity	Analyses	Global rating
Bellizzi and Blank (2007)	Prostate	Survivor	Cross-sectional	Single-item question about survivor identity (could only encorse one item) & the The Positive and Negative Affect Schedule (PANAS).	490 (men, 49-88yrs, mean age = 70yrs)	USA	2	3	n/a	3	3	n/a	n/a	Descriptives, t-tests & two hierarchical linear regressions	3
Chambers et al. (2012)	Colorectal	Survivor	Cross-sectional	Single-item question about survivor identity (could only encorse one item), The Brief Symptom Inventory, The Satisfaction with Life Scale & a Benefit finding scale.	786	Australia	2	3	n/a	3	3	n/a	n/a	Descriptives, backward stepwise logistic regression, Wilcoxon rank-sum test, chi-square test, Wilcoxon matched-pairs signed-rank test & Kruskal–Wallis equality-of-populations rank test	3

<p>Park et al. (2009)</p>	<p>Mixed</p>	<p>Survivor (Can be multiple)</p>	<p>Cross-sectional</p>	<p>Rated agreement with four identity standards & two cancer-related risk appraisals, the Psychological Well-Being Scale, the FACIT-sp, the Brief COPE, The SF-12, The PANAS, Intrusive thoughts subscale of the Impact of Event Scale, Satisfaction with Life Scale & the Perceived Benefits Scale.</p>	<p>167 (108 women & 59 men, mean age = 46)</p>	<p>USA</p>	<p>2</p>	<p>3</p>	<p>n/a</p>	<p>3</p>	<p>3</p>	<p>n/a</p>	<p>n/a</p>	<p>Descriptives, point-biserial and Pearson correlations & linear multiple regression</p>	<p>3</p>
<p>Salokari et al. (1986)</p>	<p>Breast</p>	<p>Survivor</p>	<p>Cohort analytic</p>	<p>Draw-a-person test, self-rated self-concept test, Mental Health questionnaire, & body image and related attitudes were measured in the questionnaires & via interview.</p>	<p>Not stated</p>	<p>Finland</p>	<p>3</p>	<p>3</p>	<p>3</p>	<p>3</p>	<p>3</p>	<p>3</p>	<p>n/a</p>	<p>Descriptives</p>	<p>3</p>

Zaider et al. (2012)	Prostate	Masculine	Cross-sectional	Rated the degree to which they feel a loss of masculinity on a fivepoint Likert scale, International Index of Erectile Function, sexual bother subscale of the Prostate Health-Related Quality-of-Life questionnaire, "marital affection" subscale of the Prostate Cancer Quality of life subscales.	75 (men, mean age = 61yrs)	USA	2	3	n/a	3	3	n/a	n/a	Descriptives, Pearson product correlations, multivariate analysis, regression analyses	3
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1= strong, 2= moderate, 3= weak

Appendix D: A Summary of the Quality Appraisal of the Twenty Five Qualitative Studies Included in the Review, Using the CASP Tool (2006)

First author and year	Primary Cancer	Identity Focus	Analysis Method	Sample	Country	Aim	Qualitative method appropriate	Appropriate research design	Sampling	Data collection	Reflexivity	Ethical Issues	Data Analysis	Findings	Value of the research	Overall assessment (1=excellent, 2=good, 3=borderline, 4=poor)
Arrington (2003)	Prostate	Sexual	Narrative	16 (men)	USA	✓	✓	✓	P	✓	x	✓	P	✓	P	2
Beckmann et al. (1983)	Breast	Sexual	Not stated	22 (11 tumerectomised and 11 mastectomied matched, 32-53yrs, median = 50yrs)	Denmark	✓	✓	x	n/a	✓	x	P	x	P	P	3
Becvar (1996)	Breast	Feminine	First-person account	1 (woman)	USA	✓	✓	✓	P	✓	x	n/a	n/a	P	P	3

Boehmer and White (2012)	Breast	Sexual minority (lesbian, bisexual, women who partner with women)	Grounded theory	22 (women, 43-69yrs, mean = 55yrs)	USA	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	1
Bokhour et al. (2007)	Prostate (early stage)	Physical, personal and social	Narrative	2 (men, 74 & 57 yrs)	USA	✓	✓	✓	P	✓	P	x	✓	P	P		2
Bradley, Calvert, Pitts, and Redman (2001)	Gynaecological (early stage)	Illness identity	Grounded theory	12 (women, 28-75 yrs)	UK	✓	✓	✓	P	✓	x	✓	P	P	P		2
Carpenter et al. (1999)	Breast	Self	Narrative	60 (and 60 matched controls, all women, 35-78yrs, mean = 54yrs)	USA	✓	✓	✓	P	✓	x	✓	P	P	✓		2
Clarke et al. (2011)	Oesophageal	Physical, social and personal	Interpretative Phenomenological Analysis	5 (3 women & 2 men, 56-77yrs)	UK	✓	✓	✓	P	✓	P	✓	✓	P	✓		2
Deimling et al. (2007)	Older adult mixed (breast, colorectal or prostate)	Survivor	Not stated	371 (60yrs+ old)	USA	✓	✓	x	P	P	P	x	x	P	P		3
Kaiser (2008)	Breast	Survivor	Grounded theory	39 (women, 28-87 yrs, mean=52yrs)	USA	✓	✓	✓	P	✓	x	P	P	✓	✓		2
Karnilowicz (2011)	Prostate	Self	First-person account	1 (man, 50yrs)	Australia	✓	✓	✓	P	✓	x	n/a	✓	P	P		3
Klaeson and Bertero (2008)	Breast (menopause after treatment)	Sexual	Empirical phenomenological psychological	6 (women, 38-38yrs, mean = 45yrs)	Sweden	✓	✓	✓	P	✓	x	✓	✓	P	✓		2
Komatsu et al. (2014)	Cervical	Feminine	Grounded theory	15 (women, 25-38yrs, mean = 32yrs)	Japan	✓	✓	✓	P	✓	P	✓	P	P	P		2
Little et al. (2002)	Mixed (colon, Hodgkin's lymphoma or hepatoblastoma)	Personal	Grounded theory	13 (7 men & 6 women, 13-89yrs)	Australia	✓	✓	✓	x	✓	✓	x	✓	P	P		2

Maliski et al. (2008)	Prostate	Masculine	Grounded theory	95 (60 Latino and 35 African American/Black men, 50-70+ yrs)	USA	✓	✓	✓	P	✓	x	✓	P	P	P	2
Manderson and Stirling (2007)	Breast	Physical	Narrative	38 (20 interviewed & 18 gave views via mail, 35-78 yrs, mean = 58yrs)	Australia	✓	✓	✓	x	✓	x	P	P	P	P	2
McCorry et al. (2009)	Oesophageal	General changes	Thematic	12 (9 men & 3 women, 46-85 yrs & 10 carers)	UK	✓	✓	✓	P	✓	x	✓	✓	✓	P	2
Miller (2005)	Prostate	Self	First-person account	1 (man, 54yrs)	USA	x	✓	x	n/a	x	x	x	x	P	P	3
Morris et al. (2011)	Breast	Survivor	Interpretative Phenomenological Analysis	37 (new peer support event members interviewed & 10 who had taken part in multiple events gave written accounts, mean age = 50yrs)	USA & Australia	✓	✓	✓	P	✓	P	✓	✓	P	P	2
Petersen and Matuschka (2004)	Breast	Sexuality	Journalist interview	1 (woman)	USA	x	✓	x	n/a	P	x	n/a	x	x	x	4
Shapiro et al. (1997)	Breast (experienced menopause after treatment)	General	Narrative	3 (women, 35, aged 42 & 48, & their partners)	Canada	✓	✓	✓	P	✓	x	P	P	P	P	2
Sinding et al. (2004)	Mixed (breast or gynaecological)	Lesbians (women who partner with women)	Participatory action research model	26 (women, 36-72yrs, mean = 50yrs)	Canada	✓	✓	✓	P	✓	x	x	✓	✓	P	2

Tindle et al. (2009)	Young adult mixed (Hodgkin lymphoma, non-Hodgkin lymphoma & ganglio-neuroblastoma)	Self and sexual	First-person accounts	3 (women, aged 27, 26 & 29)	UK & Australia	✓	✓	✓	x	✓	x	n/a	P	P	P	2
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P = Criteria partially met.

Appendix E: Identity Themes from the 25 Qualitative Studies, Listing the Studies Relevant to Each Theme

Theme	Specific findings	Number of studies	Study authors
Healthy		15	Arrington, 2003; Becvar, 1996; Bradley et al., 2001; Clarke et al., 2011; Karnilowicz, 2011; Klaeson & Bertero, 2008; Komatsu et al., 2014; Little, et al., 2002; Maliski et al., 2008; Manderson & Stirling, 2007; McCorry et al., 2009; Miller, 2005; Petersen & Matuschka, 2004; Sinding et al., 2004; Tindle et al., 2009.
	Loss of healthy identity	9	Arrington, 2003; Becvar, 1996; Klaeson & Bertero, 2008; Komatsu et al., 2014; Maliski et al., 2008; Manderson & Stirling, 2007; McCorry et al., 2009; Miller, 2005; Tindle et al., 2009.
	Unable to eat properly	4	Clarke, et al., 2011; Klaeson & Bertero, 2008; Little et al., 2002; McCorry et al., 2009.
	Changed sexual functioning	6	Becvar, 1996; Karnilowicz, 2011; Klaeson & Bertero, 2008; Maliski et al., 2008; Miller, 2005; Tindle et al., 2009.
	Loss of fertility	4	Becvar, 1996; Klaeson & Bertero, 2008; Maliski et al., 2008; Tindle et al., 2009.
	Change in appearance	7	Becvar, 1996; Klaeson & Bertero, 2008; Little et al., 2002; Manderson & Stirling, 2007; Miller, 2005; Petersen & Matuschka, 2004; Tindle et al., 2009.
	Different from others	4	McCorry et al., 2009; Miller, 2005; Sinding et al., 2004; Tindle et al., 2009.
	Expected recovery	2	Klaeson & Bertero, 2008; Tindle et al., 2009.
	Prioritised healthy identity	7	Arrington, 2003; Becvar, 1996; Clarke et al., 2011; Karnilowicz, 2011; Little et al., 2002; Maliski et al., 2008; McCorry et al., 2009.
	Vulnerable	5	Becvar, 1996; Bradley et al., 2001; Clarke et al., 2011; Jones et al., 2011; McCorry et al., 2009.
Cancer patient		5	Becvar, 1996; Bokhour et al., 2007; Clarke et al., 2011; Klaeson & Bertero, 2008; Tindle et al., 2009.
	Felt like just a cancer patient	2	Klaeson & Bertero, 2008; Tindle et al., 2009.
	Not just a cancer patient	3	Becvar, 1996; Bokhour et al., 2007; Clarke et al., 2011.
Survivor		8	Clarke et al., 2011; Deimling et al., 2007; Kaiser, 2008; Little et al., 2002; Maliski et al., 2008; Morris, et al., 2011 ; Petersen & Matuschka, 2004; Tindle et al., 2009.
	Survivor identity	3	Deimling, et al., 2007; Kaiser, 2008; Morris, et al., 2011.
	Normal identity	5	Clarke et al., 2011; Little et al., 2002; Maliski et al., 2008; Petersen & Matuschka, 2004; Tindle et al., 2009.
	Peer-support	2	Clarke et al., 2011; Petersen & Matuschka, 2004.
Sexuality		12	Arrington, 2003; Beckmann et al., 1983; Becvar, 1996; Boehmer & White, 2012; Bokhour et al., 2007; Klaeson & Bertero, 2008; Komatsu et al., 2014; Maliski et al., 2008; Manderson & Stirling, 2007; Miller, 2005; Petersen & Matuschka, 2004; Sinding et al., 2004; Tindle et al., 2009.

	Loss of fertility and attractiveness	6	Beckmann, et al., 1983; Becvar, 1996; Klaeson & Bertero, 2008; Manderson & Stirling, 2007; Petersen & Matuschka, 2004; Tindle et al., 2009.
	Sexual functioning	8	Arrington, 2003; Beckmann et al. 1983; Becvar, 1996; Bokhour et al., 2007; Klaeson & Bertero, 2008; Komatsu et al., 2014; Miller, 2005; Tindle et al., 2009.
	Sexual minority status	2	Boehmer & White, 2012; Sinding et al., 2004.
Masculinity and Femininity		10	Arrington, 2003; Becvar, 1996; Boehmer & White, 2012; Bokhour et al., 2007; Klaeson & Bertero, 2008; Komatsu et al., 2014; Maliski et al., 2008; Miller, 2005; Sinding et al., 2004; Tindle et al., 2009.
	Sexual functioning	6	Arrington, 2003; Becvar, 1996; Bokhour et al., 2007; Klaeson & Bertero, 2008; Maliski et al., 2008; Miller, 2005.
	Loss of fertility	3	Becvar, 1996; Klaeson & Bertero, 2008; Komatsu et al., 2014.
	Incontinence	1	Arrington, 2003.
	Inability to provide for others	1	Maliski et al., 2008.
	Inability to care for others	2	Becvar, 1996; Klaeson & Bertero, 2008.
	Appearance	5	Beckmann et al., 1983; Becvar, 1996; Manderson & Stirling, 2007; Petersen & Matuschka, 2004; Tindle et al., 2009.
	Loss of femininity/masculinity	3	Klaeson & Bertero, 2008; Miller, 2005; Tindle et al., 2009.
	Sexual minority status	2	Boehmer & White, 2012; Sinding et al., 2004.
	Redefined	4	Bokhour et al., 2007; Komatsu et al., 2014; Maliski et al., 2008; Tindle et al., 2009.
Independent and caregiver identities versus a dependent identity		9	Arrington, 2003; Becvar, 1996; Clarke et al., 2011; Klaeson & Bertero, 2008; Little et al., 2002; Maliski et al., 2008; McCorry et al., 2009; Shapiro, et al., 1997; Tindle et al., 2009.
	Independence	3	Arrington, 2003; Maliski et al., 2008; Tindle et al., 2009
	Caregiver	4	Becvar, 1996; Clarke et al., 2011; Klaeson & Bertero, 2008; Little et al., 2002
	Family role	4	Clarke et al., 2011; Little et al., 2002; McCorry et al., 2009; Shapiro, et al., 1997
	Reclaiming roles	4	Becvar, 1996; Clarke et al., 2011; Little et al., 2002; Tindle et al., 2009
	Redefine	1	Maliski et al., 2008
Occupation		9	Bokhour et al., 2007; Brockopp, & Andrykowski, 1999; Carpenter et al. 1999; Clarke et al., 2011; Little et al., 2002; Maliski et al., 2008; McCorry et al., 2009; Miller, 2005; Petersen & Matuschka, 2004; Shapiro et al., 1997
Coherence		15	Beckmann et al., 1983; Becvar, 1996; Bokhour et al., 2007; Carpenter et al., 1999; Deimling et al., 2007; Karnilowicz, 2011; Klaeson & Bertero, 2008; Little et al., 2002; Maliski et al., 2008; Manderson & Stirling, 2007; Miller, 2005; Petersen & Matuschka, 2004; Shapiro et al., 1997; Tindle et al., 2009.

DOCTORATE IN CLINICAL PSYCHOLOGY

Major Research Project

**Identity and Meaning Making in the Post-Treatment Phase for Cancer: An
Interpretative Phenomenological Analysis**

Sarah Masson

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The author certifies that all material in this thesis which is not my own work has been identified and that no material has previously been submitted and approved for the award of a degree by this or any other University.

Abstract

Purpose

Many lives are affected by cancer. The number of people in England who have had a diagnosis of cancer exceeds one million. Previous research shows that one third of patients have unmet needs post-discharge from cancer treatment, including psychological issues such as negative impacts on self-identity and a lack of meaning in life. Studies have identified identity as an important factor in meaning making, but evidence regarding cancer's impact on identity is limited to specific cancer sites and specific identity roles. Little is known about cancer's general impact on global identity or how threats to identity relate to meaning making. The aim of this study was to understand patients' experiences of cancer's impact on their identity and what sense they made of these experiences.

Methods

Twelve participants in the post-treatment phase of cancer shared their experiences in individual semi-structured interviews. Key themes regarding identity and meaning making in the post-treatment phase were identified using interpretative phenomenological analysis (IPA).

Results and Conclusions

Four key themes in the participants' experiences were identified. These were 1) disrupted identity roles, 2) highlights what is important, 3) focused on priorities, and 4) reducing awareness of loss and uncertainty. Relevant literature and implications for future research and clinical practice are discussed.

Keywords

Cancer, oncology, survivorship, identity, meaning making

Introduction

The number of people in England who have received a diagnosis of cancer exceeds one million and is expected to rise to over three million by 2030 (DoH, 2010). One third of patients post-discharge from cancer treatment have been found to have unmet needs, including psychological needs (Armes et al., 2009). The National Cancer Survivorship Initiative was launched in 2009 in recognition of the need for further support for patients in the post-treatment phase. It emphasised a more holistic approach, involving assessment and individually tailored care plans, which take into account patients' physical, psychological, spiritual and psychosocial needs (DoH, 2010). In addition to well documented psychological survivorship issues such as anxiety, depression, isolation and negative impacts on self-image, cancer can also impact on an individual's sense of self-identity (DoH, 2010).

The cancer journey involves a multitude of novel experiences that are likely to threaten the individual's identity and sense of meaning, causing psychological distress (Brennan, 2001). Studies have found that for some patients with cancer their sense of identity was threatened (e.g. Hensch & Danielson, 2009), they had to reconstruct a coherent identity (e.g. Carpenter, Brockopp, & Andrykowski, 1999), their ability to make meaning of their cancer diagnosis was impeded (e.g. Little, Paul Jordens, & Sayers, 2002) and they needed time to reflect and make meaning (e.g. Jones, Parker-Raley, & Barczyk, 2011). However, the majority of such studies focused upon specific tumour sites (e.g. breast cancer) and specific identity roles (e.g. masculinity) rather than common experiences amongst cancer patients or cancer's impact on identity as a whole. Hensch and Danielson's (2009) review of studies exploring the existential concerns of individuals with cancer found identity was an important

factor and was particularly related to disrupted meaning making, making it difficult for individuals to establish a sense of purpose. Yalom (1980) suggested that a coherent sense of identity is vital in establishing a sense of meaning: a sense of direction, purpose or a goal to fulfil. This is important as meaning has been equated with 'fullness of life' (Maddi, 1967; Rogers, 1966) and for cancer patients, meaning making plays a fundamental part in coping (Mullen, Smith, & Hill, 1993). However, between a quarter and half of all cancer patients would like support with finding meaning in their lives (Moadel et al., 1999). Yalom (1980) proposed that an identity crisis can result in a sense of meaninglessness, causing considerable distress. However, little is known about how threats to individuals with cancers; identities are related to their ability to make meaning or what overall impact cancer has on global identity.

The Present Study

This study aimed to add to the body of literature regarding the needs of patients in the post-treatment phase for cancer. Research regarding cancer's impact on the individual's sense of identity and its relation to their sense of meaning is limited and would benefit from further exploration. Interpretative phenomenological analysis (IPA) was used to explore the experiences of those in remission, across several cancer types, who had finished treatment with curative intent in the last year. Both the participant and researcher were involved in making sense of the participant's experiences.

For the purposes of this study, 'meaning' was defined as the goals, fundamental expectations and assumptions about the world which give life purpose and order (Park & Folkman, 1997). The general consensus is that the essential characteristics of identity include embodiment, continuity and memory

(Little et al., 2002), that identity formation involves both personal and contextual factors (Chickering & Reisser, 1993; Erikson, 1968, 1980), and that identity is not fixed, but continuously reconstructed (Gergen, 1991; Greenwald, 1980). Bosma and Kunnen's (2001) model of identity development postulates that new experiences and information need to be incorporated into the individual's identity.

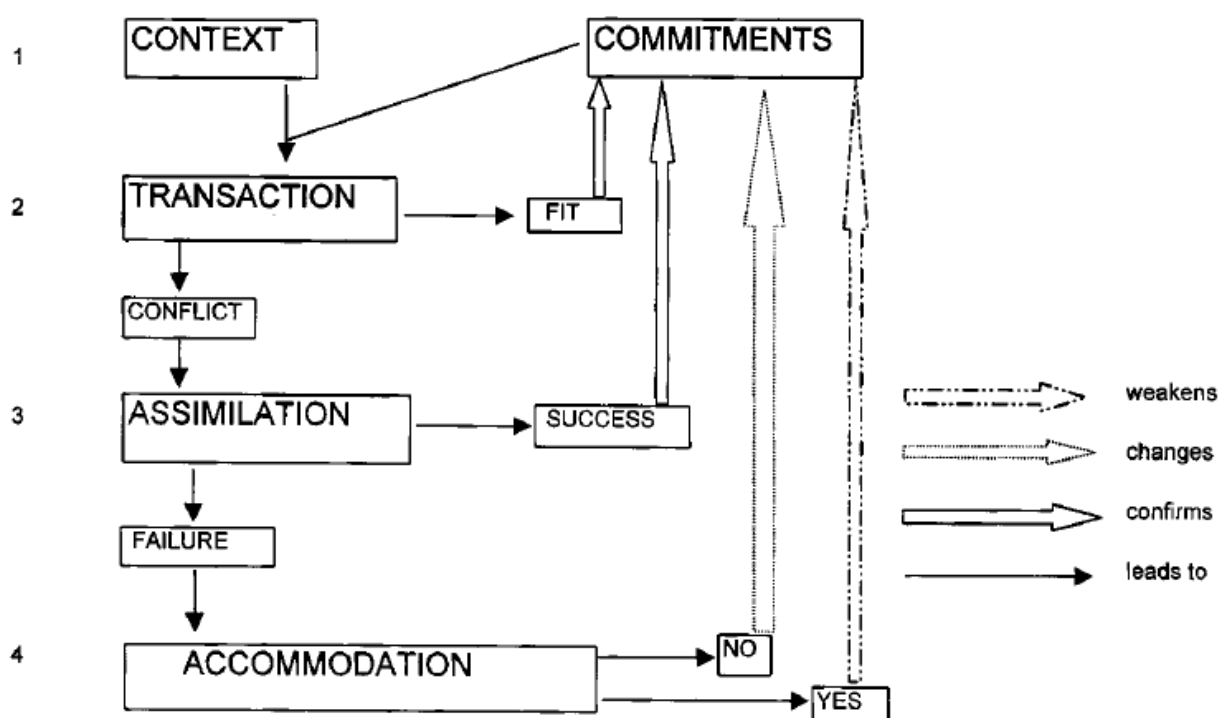


Fig. 2 Bosma and Kunnen's (2001) schematic representation of identity development (p. 22)

This model stipulates that identity gives rise to personal commitments, values and purpose (meaning), against which new information is compared⁶. When new information is congruent with the individual's identity and values

⁶ See Figure 2: Bosma and Kunnen's (2001) schematic representation of identity development (p. 22)

there is no threat to these internal constructs. However, if the two are incongruent, conflict between the lived experience and the individual's internal representation will result, known as cognitive dissonance, resulting in psychological distress (Festinger, 1957). Humans inherently try to reduce dissonance, known as the 'completion tendency' (Horowitz, 1986). This results in a drive to ideally change the interpretation of the new information to fit the internal model (assimilation) or, if this is not possible, changing the internal model to incorporate the information (accommodation). The latter process is not easy, occurring iteratively with a weakening of commitments over time. Once successful, cognitive dissonance will be resolved making the new information more predictable and increasing internal consistency. Therefore, after cancer treatment individuals can assimilate the experience into their current identity and meaning, returning to 'normal', or they can accommodate their identity and meaning to incorporate their experiences, becoming a 'different person'. Fife (1994) proposed that, in the case of life-threatening illness, the accommodated new meaning facilitates identity coherence and makes the situation seem more predictable, re-establishing a sense of purpose.⁷

⁷ See Figure 3: The process of constructing meaning in response to life-threatening illness from Fife (1994, p. 311)

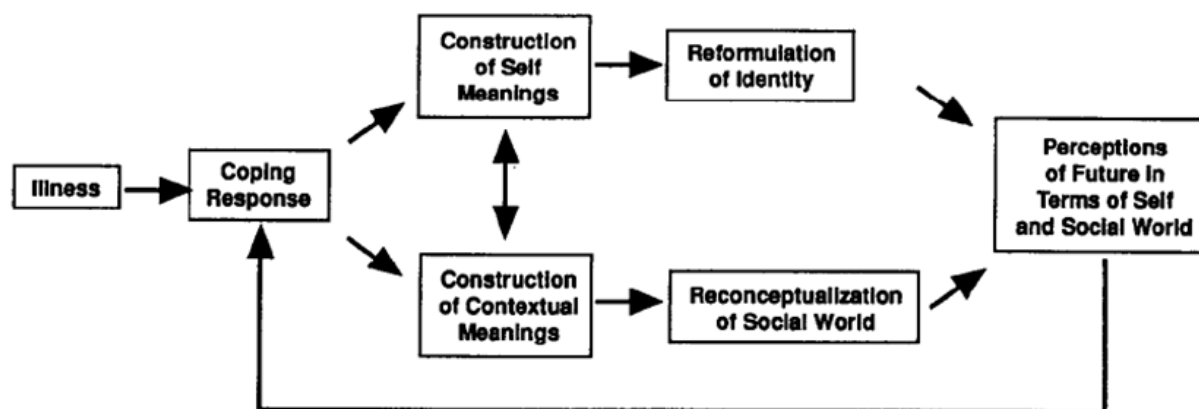


Fig. 3 The process of constructing meaning in response to life-threatening illness from Fife (1994, p. 311)

These existing evidence and theories informed the researcher about the subject area. However, research questions were broad to enable participants to identify experiences and concepts pertinent to their experience and their understanding of these experiences. The findings were then compared to existing literature.

The aims of the study consisted of understanding participants' experiences of cancer's impact on their identities in the post-treatment phase; and whether they felt these experiences had impacted on their meaning making, what they valued in life. This information will enable clinicians and service providers to better support patients post-treatment, particularly those who have difficulty reconstructing their sense of identity and/or subsequently re-establishing a sense of meaning.

Method

Participants

Participants were eligible for the study if they were aged 18-65, a fluent English speaker, had been diagnosed with cancer (any type), had finished

treatment with curative intent within the last five years and were in remission. Individuals who had had any other life threatening illness or chronic illness in the last five years were excluded as these experiences may confound any cancer-related experiences. Participant demographics and disease-related information were collected pre-interview.⁸

Twelve participants were recruited, enabling a detailed understanding of each participant's experience whilst providing sufficient cases to enable the identification of meaningful differences and similarities between them.

Service User Involvement

The views of the Thames Valley Cancer Research Network Consumer Research Partnership (TVCRN CRP) were sought and incorporated into the study methodology, recruitment process, participant information and interview schedule.

Recruitment and Ethical Considerations

This study was approved by the Frenchay Research Ethics Committee, the University of Exeter School of Psychology Ethics Committee and the participating hospital's research and development Team.⁹¹⁰¹¹ The study was performed in accordance with the ethical standards laid down in the Declaration of Helsinki (1964) and later amendments.

⁸ See Table 3: Participant demographics and disease related variables

⁹ See Appendix F: Approval from Frenchay Research Ethics Committee, NHS Health Research Authority; and Appendix G: NHS Health Research Authority acknowledgement of conditional documents.

¹⁰ See Appendix H: Approval from the University of Exeter Psychology Ethics Committee.

¹¹ See Appendix I: Research and Development Approval from the Participating NHS Foundation Trust.

Participants were recruited through a cancer service in a district general hospital in the south west of England, using a purposive sampling method, between November 2013 and March 2014. The hospital serves both urban and rural communities and has 400 inpatient beds. The cancer service provides inpatient, day-case and outpatient services for cancer treatments for a population of over 340,000 local residents. Each year the service diagnoses over 2,300 new cases of cancer. It has a ten-bedded, highly specialist, inpatient ward. Clinicians from the participating cancer service initially identified eligible patients and asked them whether they would be happy to be contacted about the research study. In order to recruit a representative sample, individual cancer services, treating different cancer sites, were approached for one to two participants each. When more than this number were identified, patients were selected to ensure a variety of demographics were represented, e.g. a range of ages. This ensured that patients with a range of cancers were recruited to help explore experiences common across cancer types. Individuals who said yes were given or sent a participant information sheet. If the individual was happy to participate a meeting was arranged with the researcher at the hospital.¹² All participants were fully informed about the study, gave consent to participate and were clear that they could withdraw at any time without giving a reason.¹³ Fourteen participants were contacted, one of whom withdrew before the interview and another was not available for interview due to ill health in the timeframe available. However, the remaining twelve gave informed consent and were interviewed.

¹² See Appendix J: The Participant Information Sheet.

¹³ See Appendix K: The Consent Form.

During the interview, the researcher was sensitive to any signs of distress; ensuring participants did not feel obligated to answer any questions. Participants were encouraged to contact the research team if, after the interview, they experienced any distress. After the interview a letter was sent, with the participant's permission, informing their GP of their participation.¹⁴

All participant data was anonymised. The study findings will be disseminated to participants, the participating cancer service, TVCRN, and to wider services and organisations interested in cancer survivorship.¹⁵

¹⁴ See Appendix L: Letter to GP informing participant's participation in the study.

¹⁵ See Appendix M: Dissemination statement.

Table 3
Participant demographics and disease related variables

Participant Identifier	Gender	Age	Ethnicity	Primary cancer	Treatment type	Time since diagnosis	Time since completed treatment with curative intent
P1	Male	49	White British	Prostate	Surgery	1 year, 1 month	1 month
P2	Male	40	White British	Bladder	Surgery	1 year, 4 months	5 months
P3	Male	57	White British	Rectal	Surgery, chemotherapy and radiotherapy	1 year, 6 months	5 months
P4	Male	28	White British	Testicular	Surgery	7 months	7 months
P5	Male	59	White British	Renal	Surgery	8 months	7 months
P6	Female	63	White British	Breast	Surgery and radiotherapy	2 years, 7 months	2 years, 2 months
P7	Female	57	White British	Colon	Surgery	1 year, 3 months	1 years, 2 months
P8	Female	48	White British	Breast	Surgery, chemotherapy, radiotherapy and Herceptin	1 year, 7 months	2 months
P9	Female	50	British Asian	Breast	Surgery, chemotherapy and Herceptin	1 year, 7 months	2 months
P10	Female	28	White British	Colon	Surgery and chemotherapy	1 year, 4 months	9 months
P11	Female	27	White British	Cervical	Chemotherapy and radiotherapy	2 years, 2 months	1 year, 11 months
P12	Female	37	White British	Hodgkin's lymphoma	Chemotherapy	1 year	2 months

Interview

An interview schedule was developed to guide the researcher, ensuring that a detailed account of the relevant topics was obtained.¹⁶ These topics were:

- Identity pre-cancer;
- Identity post-cancer;
- Comparison of pre- and post-cancer identities;
- Identity changes and meaning making, if appropriate.

Questions were open and expansive, enabling participants to talk at length about their experiences. The researcher used these questions flexibly, altering the sequence and wording to fit with the participant's account. Additional prompts were used, where necessary, to gain clarification and elicit more information.

Based on the participants' own accounts, the researcher drew out the identity roles, with descriptions, in spider-diagrams of their pre- and post-cancer identities.¹⁷ These were used as visual aids to support participants when communicating their experiences, helping capture all of the parts of their identity they felt relevant and checking the researcher's understanding. The participants also had the opportunity to compare their pre- and post-cancer identity descriptions, commenting on any similarities and differences they felt pertinent and what sense they made of these observations.

The interviews were audio-recorded and transcribed verbatim. Interviews ranged from 52 to 100 minutes in duration.

¹⁶ See Appendix N: Semi-structured Interview Schedule.

¹⁷ See Figure 4: An example spider-diagram of a person's identity.

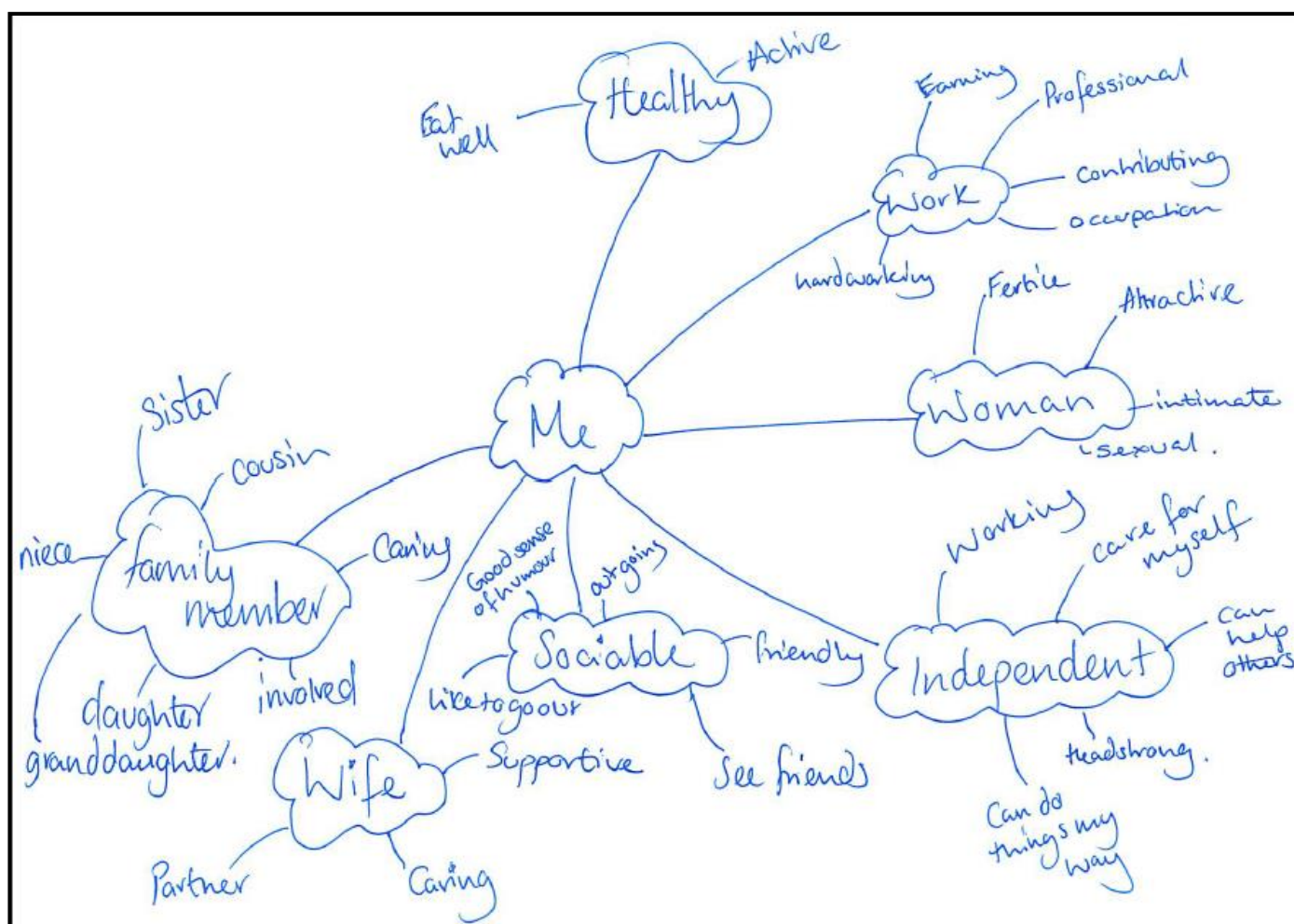


Fig. 4 An example spider-diagram of a person's identity

Analysis

Interpretative phenomenological analysis

To obtain an understanding of how participants made sense of their experiences in the post-treatment phase, IPA (Smith, Flowers, & Larkin, 2009) was employed. IPA is idiographic, exploring in detail the lived experience of the individual and the sense they make of these experiences. This method allows the exploration of the participant's perspective, whilst acknowledging the impact of the researcher's world view, and the interaction between the two, upon the interpretation (Willig, 2001). It enables researchers to make links between the experiences and understandings of participants, and theoretical

conceptualisations (Smith et al., 2009). This approach draws from three philosophical areas: idiography, phenomenology and hermeneutics. Smith and colleagues (Smith et al., 2009) give a detailed account of these approaches which will be summarised here.

Idiography. Idiographic refers to a concern for the particular. IPA does this in two ways: focusing on 1) the specific details of an experience, and 2) specific experiences of specific people. Any generalisations are, therefore, made cautiously and are located in the particular experience. The phenomena being studied were not seen as solely the property of the individual, but rather their unique perspective on their relationship to them.

Phenomenology. Phenomenology is the philosophic study of experience. IPA attempts to idiographically capture particular experiences of particular people. It focuses on the individual's perspective and meaning, unique to their embodied experience of, and relationship with, the world. The researcher interprets these experiences, focusing on how the individual makes sense of them, being mindful that the person is embedded within a world of relationships, culture and language.

Hermeneutics. Hermeneutics is the philosophical theory of interpretation, concerned with the nature of interpretation and its potential impact on the original intentions or meanings of the author of the account. IPA particularly draws on the work of Heidegger (1962) and Gadamer (1975). Heidegger (1962) highlighted the importance of acknowledging how the fore-conceptions of the interpreter shapes the interpretation and that usually the process of interpretation itself brings relevant pre-conceptions to the fore. Gadamer (1975) proposed that interpretation itself enables the comparison of various pre-conceptions which are modified and compared throughout the sense making

process. The authors stated that the focus of the interpretation was on the meaning of the account, which would be influenced by the context in which the interpretation was made. The use of the hermeneutic circle, that to understand the whole you need to look at the parts and vice versa, is central to the iterative process of IPA.

Alternative Qualitative Methods

Other qualitative methods were considered. Grounded theory approaches (Charmaz, 2006; Glaser & Strauss, 1967) could have been used to develop a theoretical account of cancer's impact on identity post-treatment. The language and social constructionist focus of discourse analysis would have provided an understanding of participants' discourse, for example in relation to power (Kendall & Wickham, 1998) or social interaction (Sidnell & Stivers, 2013). Thematic analysis (Braun & Clarke, 2006) would have led to the generation of themes pertinent to the participant's experiences. Narrative analysis (Crossley, 2000; Gergen & Gergen, 1988) could have been used to provide a greater understanding of story structures used by participants rather than participants' idiographic experiences and sense-making. All of these approaches were relevant. However, IPA was chosen to enable a focus on, and give voice to, participants' experiences and sense making, which would be grounded in their experience but linked to relevant psychological concepts (Larkin & Thompson, 2012).

Analysis Process

Smith and colleagues' (2009) guidance for conducting IPA were followed.¹⁸

Table 4
IPA procedure (Smith et al., 2009)

<u>Stage number</u>	<u>Stage title</u>	<u>Description</u>
1	Reading and re-reading	Listening to the audio and reading the transcript, author notes anything of interest or significance.
2	Initial noting	Producing a detailed set of notes and comments on the data (descriptive, linguistic and conceptual).
3	Developing emerging themes	Looking for emerging themes and attempting to reduce the volume of detail whilst maintaining complexity.
4	Moving to the next case	Moving onto the next transcript and repeating the process.
5	Searching for connections between emergent themes	Drawing together the emerging themes and exploring a spatial representation of how they relate to each other (including abstraction, subsumption and polarisation).
6	Looking for patterns across cases	Measuring recurrence across cases using a table of themes which may include re-labelling and reconfiguring of themes.

In summary, the researcher was immersed in the participant's account, making notes about significant content related to how participants described experiences relevant to their identity and meaning, i.e. what they valued in life, post-treatment, as well as what sense they had made of these experiences.¹⁹ After each reading of the transcript, observations were noted, as well as any recollections from the interview itself and the researcher's reflections of their

¹⁸ See Table 4: IPA Procedure for an outline of the procedure followed.

¹⁹ See Appendix O: Example of transcript coding

influence on the coding. This helped gain a coherent sense of the account as a whole, areas of contradiction, ambivalence, resistance or incoherence.

The initial transcript comments were divided into discrete chunks of transcript. This allowed the identification of patterns, inter-relationships and connections between themes, notes and participant experiences. Themes that were not related to identity or meaning making were discarded, e.g. general themes regarding 'time'. Superordinate themes were initially identified through abstraction, grouping together similar emergent themes, e.g. being healthy, being athletic, being fit. Groups of emergent themes focusing on opposite ends of the same concept or continuum were collapsed into super-ordinate themes through polarisation, e.g. focusing on the positives and compartmentalising the negative things. Numeration was used to identify common themes noting the frequency with which they were reported. Some emergent themes were grouped based on their function, e.g. withdrawing from others and withdrawing from activities were functions of compartmentalising negatives.

The themes were mapped out on note cards on a wall and grouped into superordinate themes and spatially positioned to represent relationships between themes. This map was compared with the participant's overall experience and adjusted as necessary. Themes were then checked against transcript excerpts to check the fidelity of the theme to the participant's specific experiences.

This process was repeated for each participant, the thematic mapping was amended as necessary. The map of themes was then reviewed against individual participant's experiences and transcript excerpts. This enabled the identification and removal of poorly evidenced interpretations, retaining an idiographic focus. This process was supervised by research supervisors.

QSR International's NVivo 9 software (2010) was used to conduct the analysis: coding transcripts, keeping process notes, identifying emergent themes and then checking themes across participant accounts.

Results

Participants' experiences were detailed, with many idiosyncrasies. The overarching themes were mapped into a graphic representation.²⁰ This article focuses primarily on themes central to participants' experiences relating to identity and meaning making. Four superordinate themes commonly representing participants' experiences were identified: 1) disrupted identity roles; 2) highlights what's important; 3) focused on priorities 4) reducing awareness of loss and uncertainty. The number of participants who experienced each theme is shown in Table 5. Idiographic excerpts will be used to illustrate experiences relevant to each theme.

²⁰ See Figure 5: An overview of the themes emerging

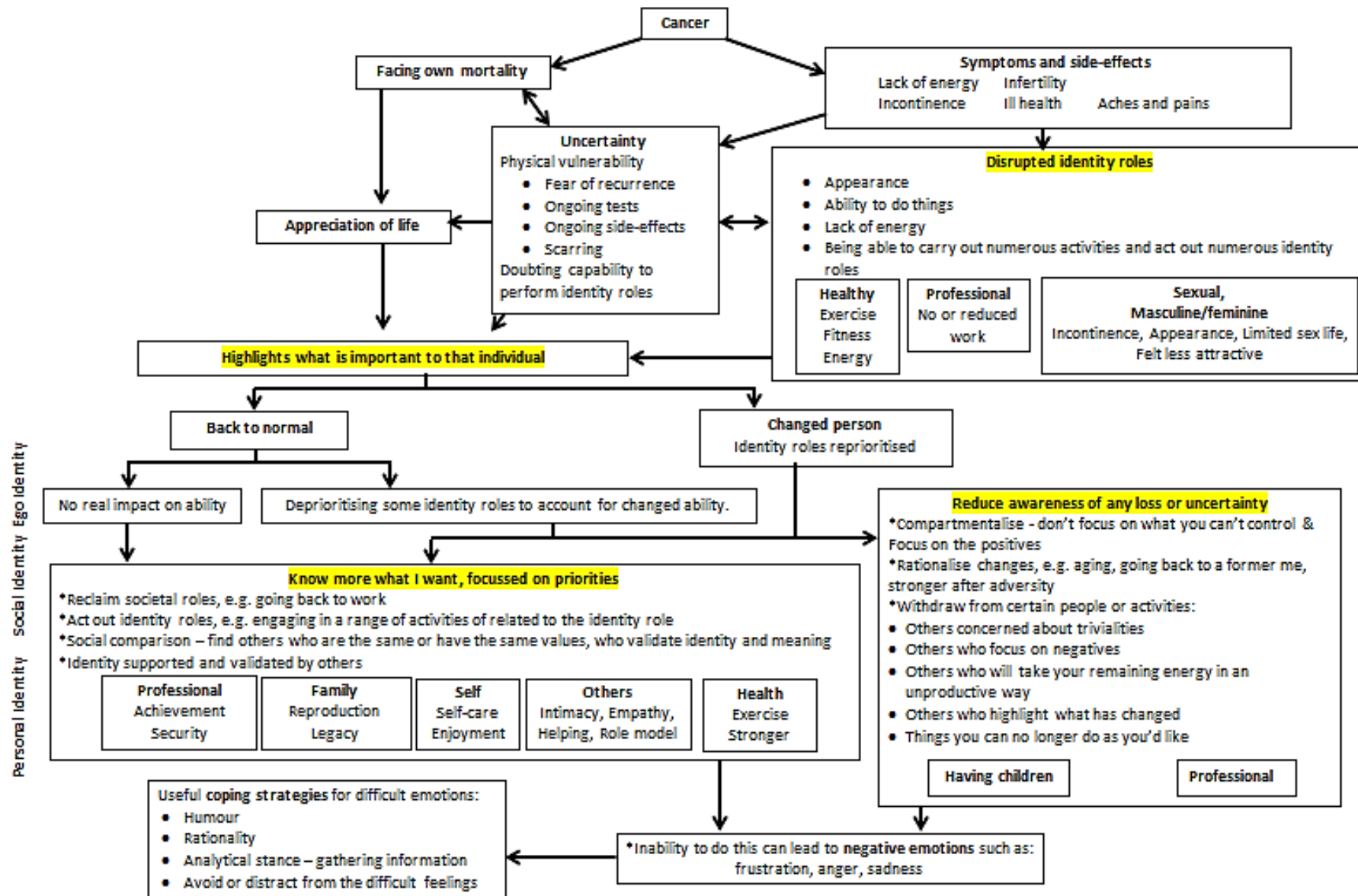


Fig. 5 An overview of the themes emerging, themes most relevant to identity are highlighted

Table 5
Table of key themes

<u>Superordinate themes (number of participants)</u>	<u>Themes (number of participants)</u>
1. Disrupted Identity roles (10)	1.1 <i>Physically vulnerable</i> (10) 1.2 <i>Sexual, feminine and masculine</i> (8) 1.3 <i>Symptoms and side-effects</i> (10)
2 Highlights what is important (12)	2.1 <i>Back to normal</i> (7) 2.1.i <i>Deprioritise affected roles</i> (6) 2.2 <i>Changed person</i> (5)
3. Focussed on priorities (12)	3.1. <i>Reclaim societal roles</i> (8) 3.2. <i>Act out identity roles</i> (12) 3.3. <i>Social comparison</i> (11) 3.4. <i>Support and validation from others</i> (12)
4. Reduce awareness of loss and uncertainty (8)	4.1 <i>Compartmentalise & prioritise what you can achieve and control</i> (4) 4.2 <i>Focus on the positives</i> (7) 4.3 <i>Rationalise the change</i> (11) 4.4 <i>Withdraw</i> 4.4i <i>From others who don't fit new priorities</i> (5) 4.4ii <i>From activities that don't fit new priorities</i> (6)

The results are the researcher's interpretation of the participants' lived experiences and the sense participants made of them, evidenced by extracts from participants' reported experiences.²¹²²

Participants experienced their identities as consisting of a variety of concepts, including personal characteristics (e.g. 'bossy'); individualised personal identity roles taken from broader socially prescribed roles (e.g. 'professional'); emotions (e.g. 'angry'); and values (e.g. 'honest'). The term

²¹ Appendix P: The identified themes and participants who experienced them.

²² Omissions in the extracts are represented as (...).

'identity role' will be used to encompass all of these identity constituents. Participants experienced the performance of certain behaviours, termed here as 'identity role repertoires', as integral to their individual identity roles. The coherence of participants' experiences varied, with some able to give clear accounts of their pre- and post-cancer identities and how they had changed, whereas other accounts lacked temporal coherence or contained ambivalence or contradictions regarding experiences of cancer's impact on identity.

1. Disrupted Identity Roles

1.1 Physically vulnerable. For the majority of participants, having cancer changed their view of themselves as a 'healthy' person, to someone who was 'physically vulnerable'. As a result, some participants felt the need to be more cautious and health conscious; for others it highlighted their mortality.

P1: "...I'm less confident I would say. You sort of feel that your body has let you down in some respects. So, certainly if you get, you know, a cold you sort of think oh my god it's all back..." (Male, 49, prostate cancer, 1 month post-treatment)

Of those who did not feel vulnerable, one did not feel she had had cancer and the other felt the cancer would be treatable if it recurred.

P7: "...So really it hasn't affected me. I don't know if I'd have had chemotherapy if I would have been different, whether it would have made me different altogether, I don't know. Because I never actually felt like I had cancer..." (Female, 57, colon cancer, 14 months post-treatment)

P4: "...That's my rationality, even if it comes back, doctor says it's 100% treatable because it will be caught and out with everything (referring to removal of the other testicle)." (Male, 28, testicular cancer, 7 months post-treatment)

1.2 Gender and sexual identities. Changes in appearance, such as scarring or mastectomy, as well as physical functioning, such as incontinence, meant many participants felt less attractive and conspicuous, disrupting their gender and/or sexual identities.

P2: "...I'm not like the biggest bloke, I'm bigger now (compared to his post-treatment self) but he (Friend) was sat there and I felt so inadequate (physically). I thought I can't be doing this and he's all like that [gestures being muscly] and I'm wetting myself into a -do you know what I mean? There was a big gap (physically), and we, there never used to [be]..." (Male, 40, bladder cancer, 5 months post-treatment)

1.3 Symptoms and side-effects. The majority of participants experienced cancer symptoms and treatment side-effects such as pain, incontinence and cognitive impairment. This meant that they were unable to perform various roles they felt were important to their identity, for example going to work, caring for loved ones and keeping fit and healthy. For half of the participants, reduced energy levels meant that they had to negotiate which identity roles to perform and to what degree.

P3: "...It's (cancer) got huge sort of implications really of like, ok how much energy have I got to do things at home? How much energy have I got to go running? Also, you know, the huge impact of work because, can I still manage doing work on the schedule and the time periods that I had before?..." (Male, 57, rectal cancer, 5 months post-treatment)

Not being able to do the things they could before resulted in a few participants feeling frustrated, inadequate or less confident that they would be able to fully reclaim previous identity roles repertoires. Two participants did not find changes in ability to do things disruptive to their identity. Both felt these changes were due to normal aging processes.

P7: "...Now my back will ache. So I have to accept that, you know, I can't do digging all day (...) but I don't think that's anything to do with the

cancer, that's just that I am getting older." (Female, 57, colon cancer, 14 months post-treatment)

2. Highlights what is Important

Having cancer, participants faced the loss, or potential loss, of their identity and/or life. This highlighted for all participants what was important in life (meaning), and for some what they had taken for granted, including particular identity roles, such as being healthy, caring, loving, responsible, giving and happy.

P11: "...So I didn't work through my treatment or anything at all. So there was no focus around my career then, obviously I was just focused on getting better. And I suppose that's when the change happened, when I went back to work. I think once you are removed from something that you've always taken for granted, because I've always worked since I was 13, I suppose, I got a paper round when I was 12, suddenly I had no... That's gone. And I suppose that's the same with (...) parenthood as well, so things that you just take for granted that's going to happen or that have always just been there, certainly when it's gone (...) Suddenly you think shit. You want that now and you can't have it." (Female, 27, cervical cancer, 23 months post-treatment)

2.1 Back to normal. For some participants, having cancer reaffirmed their values and identity. They felt that they were the same person after cancer.

P7: "...I felt a bit grim for a month or so. But once that passes and you start to get back to normal life, I don't feel any different..." (Female, 57, colon cancer, 14 months post-treatment)

2.1.i Deprioritise affected roles. Participants who felt they were the same person reported some changes, either in their lifestyles or attitudes, such as choosing to retire, cutting back activities due to lack of energy, or being less tolerant. However, the affected roles had been deprioritised, which participants did not view as a change in their identity, but instead attributed to aging, a shift in priorities or resulting from a greater appreciation of self-care.

P12: "...It's not so much (...) my job isn't really hugely important anymore, because it is (...) it's just, yeah, trying to look at it a different way... a different way of looking at things." (Female, 37, 2 months post-treatment)

2.2 Changed person. The remaining participants felt that their identity had changed, which the majority experienced as a positive. They described a period of reflection during treatment, enabling them to re-evaluate who they were and what they wanted in life. For example choosing to re-establish a pre-motherhood identity, focus on their career or invest more into their relationships.

P1: "...Being so ill and having time to think, made me reflect on that, that I didn't want to stop work... I've got more to offer than that... So, yeah I mean that has totally altered (before the cancer he wanted to retire)...I felt I had got quite a lot to offer and retiring for me was not the best thing to do, or for the world actually was not the best thing to do, because I am too young really to retire, or too young in mind..." (Male, 49, prostate cancer, 1 month post-treatment)

P6 felt the change in her identity had been detrimental. She no longer felt she knew who she was or what she should be doing. She had never felt sure of who she was, but before cancer had felt "capable of being me". Facing mortality seemed to have left her feeling old and, whilst the importance of being in a caring relationship had become clear, she felt unable to pursue this, which left her feeling "stuck in a hole".

P6: "...I can't determine where I am (...) or what I am, or who I am (...) I suppose I've just been up and down over the years, but it just seems to be worse now..." (Female, 63, breast cancer, 26 months post-treatment)

3. Focussed on Priorities

All participants reported being more focussed on what they wanted from life, including the person they wanted to be, and the majority felt motivated to

achieve it. Several subthemes were identified that impacted upon participants' experiences of how they now made sense of, and experienced, their identity.

3.1. Reclaiming societal roles. Many participants found that adopting roles within society helped to validate their identity, e.g. going back to work, or caring for children.

P10: "As I've got on and gone back to work, work has helped me get myself back to normal." (Female, 28, colon cancer, 9 months post-treatment)

3.2 Acting out identity roles. All participants talked about the importance of being able to resume identity role repertoires. This seemed to increase their confidence in the relevant identity role. Some talked about returning to pre-cancer identity roles and several even talked about being better than before, for example fitter, more hard working. Others talked about having to readjust their expectations and pace themselves with the hope that they will eventually achieve their desired level of performance within that identity role.

P5: "...A lot of people have said to me you haven't changed in the way that you, you come over (...) I don't do anything different now than I did prior to. I mean I go birding because I like me birds, I go regularly..." (Male, 59, renal cancer, 7 months post-treatment)

3.3 Social comparison. Many of the participants made comparisons with others when talking about their identity. Most participants made direct comparisons between their identity role repertoires and those of others. Participants highlighted similarities to those without cancer who had desired identities.

P5: "...He's (colleague) about two years younger than me and, I think it's (the cancer) made him think about retiring next year which will be a year

bef- you know he'll be fifty-eight, fifty-nine, something like that and well I'll be sixty when I retire..." (Male, 59, renal cancer, 7 months post-treatment)

3.4 Identity supported and validated by others. All participants experienced others' support as an important part of re-establishing their sense of identity. Participants mentioned occasions when others had affirmed their identity role by observing continuities between pre- and post-cancer identities or provided reassurance about the validity of any reclaimed or altered identity role performance.

P1: "He (friend) felt that I was fitter than I was before and I think probably I am because there was a period when I wasn't allowed to cycle (...) so I did a lot of other sports (...) and I think that was good for me to be honest (...) so yeah I probably am fitter..." (Male, 49, prostate cancer, 1 month post-treatment)

4. Reduced Awareness of Loss and Uncertainty

The importance of doing things to reduce awareness of the lost abilities or change in meaning, as well as to regain a sense of control over oneself in the face of uncertainty in ones' abilities, identity and mortality was identified as a superordinate theme within participants' experiences.

4.1 Compartmentalise and prioritise what you can achieve and control. Several participants spoke of compartmentalising parts of their identity and valued goals. This seemed to enable them to avoid thinking about lost identities or future goals (meaning) that they were not able to deprioritise, often withdrawing from activities or individuals related to lost or impaired roles. Participants instead would prioritise the identity roles they had control over, sometimes as a way of distracting from the lost or impaired identity role.

P11: "...My career has kind of replaced the fact that (she can't have children)... It's almost like my armour..." (Female, 27, cervical cancer, 23 months post-treatment)

This also helped when participants did not have sufficient energy to act out all valued identity roles as proficiently as hoped, reducing conflict between identity roles, allowing them to put these roles out of mind.

P10: "I've got to stop myself from worrying, stop myself from... I mean, I've got other things to think about. And it's prioritising my time. Like I said, time with family rather than worrying about work (...) I can switch myself off a lot more (...) I can go home now and just, you know, be with [Husband] or be with my friends without even thinking about work." (Female, 28, colon cancer, 9 months post-treatment)

Others compartmentalised the whole cancer experience, seeing it as an isolated incident.

P9: "If I completely forget about what happened last year, I'm back to where I was before." (Female, 50, breast cancer, 2 months post-treatment)

4.2 Focus on the positives. The importance of focusing on positives helped some participants to accept impaired identity role performance and maintain hope for further recovery. It was also a useful distraction from more negative aspects of identity change, such as feeling physically vulnerable or the loss of ability or confidence in previous identity roles.

P9: "Focus on something positive (...) so you don't have time to sit down and worry about your aches. Sometimes you don't even notice you have got aches and pains because you are too busy thinking about something else." (Female, 50, breast cancer, 2 months post-treatment)

4.3 Rationalise the change. Whilst talking about cancer-related identity changes, nearly all participants gave rationalisations for changes in terms of 'aging'. For all the experience was a maturing process, and for the majority it

helped them to feel more their age, in line with their peers. All compared their altered identity role repertoires with those of their peers and accepted these changes as inevitable. Younger participants talked about becoming more adult in terms of their priorities and lifestyles.

P11: "...50% of the people I went to school with would have been (...) how I am now (focusing on their career and wanting a family) (...) it's shifted things massively (...) half of this piece of paper (referring to the pre-cancer identity drawn in a spider-diagram) is clearly someone that I am not anymore. (...). I think, was just the younger me growing-up." (Female, 27, cervical cancer, 23 months post-treatment)

Whereas older participants talked about aging in terms of physical deterioration.

P6: "...I don't look as young as I did sort of five years ago even" you know. I don't feel as young as I did two years ago when I first sort of found it all, you know so I just feel as if I have aged. Yeah I do feel as if I have aged." (Female, 63, breast cancer, 26 months post-treatment)

Discussion

Four superordinate themes were identified using IPA. Key areas from these themes were: impact on identity, identity and meaning-making, identity reconstruction and defence mechanisms, which will now be considered in relation to relevant literature.

Impact on Identity

Disrupted identity roles. As in previous studies, specific identity roles, such as gender (e.g. Klaeson & Bertero, 2008), sexual (e.g. Arrington, 2003), independent (e.g. Maliski, Rivera, Connor, Lopez, & Litwin, 2008), occupational (e.g. McCorry, Dempster, Clarke, & Doyle, 2009), caregiver and family (e.g. Clarke, McCorry, & Dempster, 2011) were threatened post-treatment by

treatment side-effects, resulting in dependence and an inability to perform usual activities, such as altered sexual functioning, caring for others and working.

Participants talked about the paradox between being healthy and an ongoing fear of recurrence in terms of their 'healthy' identities and, for most, a newly acquired sense of being 'physically vulnerable'. This finding differs from Jones and colleagues' (2011) study which located this struggle within 'cancer patient' and 'survivor' identities. In fact, none of the participants talked about their identity in terms of being either a 'cancer patient' or a 'survivor'. This raises questions about the relevance of these identity roles to participants in comparison to researchers who focus on this role specifically (e.g. Deimling, Bowman, & Wagner, 2007), especially as past studies have highlighted that some participants objected to these labels or found them too simplistic (e.g. Clarke, et al., 2011; Kaiser, 2008).

Identity crisis. Some participants described a period of identity confusion during treatment, being unsure of what to prioritise or how to act, which they worked through, reclaiming and renegotiating valued identity roles. This is in keeping with the concept of 'identity crisis', when the "previous identity is no longer experienced as suitable, but a new identity is not yet established", resulting in a lack of engagement with social roles, and instability in one's character and behaviour (Levine and Cote, 2002, p. 95). For one participant the identity crisis was ongoing, resulting in a sense of meaninglessness and causing considerable distress, as Yalom (1980) hypothesised.

Identity and Meaning Making

All participants found that cancer highlighted what they had taken for granted and what was important in life (meaning), as observed in other studies

(e.g. Cayless, Forbat, Illingworth, Hubbard, & Kearney, 2010; O'Connor, Wicker and Germino, 1990). For many participants their experiences reaffirmed their life values (meaning) and identity, returning to previous identities, sometimes redefining or deprioritising identity roles that had been impacted upon by cancer, as observed in previous studies. For the remaining participants, having cancer resulted in a change in priorities both in terms of purpose in life and identity roles. These participants experienced a period of reflection on their lives and how they would like to live and act which has been observed in other cancer and chronic illness studies (e.g. Charmaz, 1994; Frank, 1991). These experiences complement the 'transformations' observed in Mulkins and Verhoef's (2004) study, in which individuals gained greater insight into who they were and how they relate to the world, providing them with avenues for improving their lives. The notion of transformation has been discussed in narrative studies, exploring ways in which the identities of patients with specific cancers (Carpenter et al., 1999; Shapiro, Angus, & Davis, 1997) or other illnesses (Frank, 1995) changed post-treatment. Whilst these narratives were present in many participants' accounts, their experiences often did not conform to just one narrative.

Shapiro and colleagues (1997) identified three narratives related to adjusting to cancer treatment: 'rebirth', the formation of a new self, separate from the pre-cancer self; 'turning point', becoming more in line with who they were rather than being different; and, 'back to normal', being fundamentally the same unchanged person. Participants' experiences in this study could be said to fit a mixture of these narratives. Some participants' experiences were ambivalent, describing feeling they were the same person yet talking about changes to identity, or feeling that they were completely different but

reconstituting past attributes. Others talked about experiencing a 'turning point' but as a result being different from before, more the person they wanted to be.

Carpenter and colleagues (1999) identified three groups: 'positive transformation', 'minimal transformation' and 'feeling stuck'. These groups varied in the extent to which participants' identities altered, and/or coherence was restored. They defined 'positive transformation' as brought on by increased self-awareness in the face of mortality, which led to changes in the self and relevant aspects of their lives, increasing their self-esteem and well-being. In 'minimal transformation' the intensity with which they faced mortality was lessened, resulting in increased self-awareness and either acceptance or reinforcement of their current self, with less desire to change, and the downplaying of any changes. In 'feeling stuck' facing mortality led to a desire to change but participants felt unclear about what changes should be made, and lacked courage and support, which resulted in low self-acceptance, self-esteem and well-being. Participants' experiences could be said to fit these descriptions. However, the degree to which cancer impacted on identity roles, particularly through lost functioning and abilities seemed an important factor in whether a participant experienced change and this is not accounted for in Carpenter and colleagues' (1999) descriptions.

Frank (1995) identified three illness narratives regarding coherent identity construction: restitution, chaos and quest. He defined 'restitution' as narrative from health, to illness and then returning to health. Chaos was defined as a disorganised narrative in which the main theme is of vulnerability and impotence, not being able to imagine life getting better. In the quest narrative cancer is described as a challenge, facilitating change. These narratives were observed in the participants' experiences. However, some participants'

narratives also supported Thomas-Maclean's (2004) suggestion that for some with cancer the restitution narrative is better understood as a 'reconstruction' narrative, as returning to prior health was no longer entirely possible.

Participants' experiences complement Bosma and Kunnen's (2001) model of identity development. Some participants appeared to assimilate their experiences, returning to 'normal'. This occurred for participants for whom cancer only disrupted identity temporarily, or in such a way that identity coherence could be re-established by reprioritising identity roles without impacting on their sense of meaning. Other participants seemed to accommodate their experiences, becoming a 'different person'. This occurred for those who were unable to conform to previously valued identity roles because of cancer's affects which could not be understood in terms of their previous global identity and meaning, resulting in a shift in identity coherence and meaning making. For nearly all participants, the meaning gleaned from their cancer experience complemented their post-treatment identity and supported any re-prioritisation of identity roles, re-establishing continuity and coherence between the past, present and future, in line with Fife's (1994) model and previous findings (Bokhour, Powel, & Clark, 2007).

Identity Reconstruction

The two superordinate themes: highlighting what is important and focusing on priorities, support Cote and Levine's (2002) model of identity resolution. This model stipulates that the dovetailing of three processes facilitates identity resolution. The first process is the development of stable identity coherence, the second is the stabilisation of character and behaviour, and the third is the acquisition of social roles. Several factors were identified in participants'

experiences that seemed to facilitate these processes and will now be discussed.

Acting out identity roles. It was important for participants to reclaim social roles and to make comparisons with others to re-establish their place in wider social structures. Acting out prescriptive social identities via idiosyncratic personal identities helped to re-establish personal agency, increasing their confidence in that identity role and global identity coherence. These findings have also been observed for those with other chronic illnesses (Charmaz, 1994).

Support and validation from others. Whether identity had changed or continued, support and validation from others was important in re-establishing identity coherence post-treatment. This has been observed with other chronic illnesses (Charmaz, 1994) and supports theories that emphasise the importance of the perceptions of others and society in the formation and validation of a stable, coherent identity (Erikson, 1968, 1980; Fife, 1994; Mead, 1934).

Focusing on the positives. Some participants found it important to focus on the positives. Fife (1994) suggested that focusing on the positives and health behaviour helps minimise illness significance, enhancing a sense of meaning in illness experiences and wider existence, and regain a sense of mastery over one's life. Positive perspectives may be a way of coping, making every effort to stay engaged with the important goals that give life structure (meaning) (Carver et al., 1993). In this way positive aspects of identity changes are emphasised. However, Willig (2011) highlights that 'thinking positively' is a common cancer discourse which is rewarded and socially desirable. Therefore, participants may be conforming to socially desirable discourses.

Defence Mechanisms

Participants' experiences of compartmentalising lost roles, focusing instead on the positives, could be understood as a defence mechanism, helping maintain a coherent identity and sense of continuity, meaning and hope.

Denial. Participants' generalised experiences complement Brennan's (2001) social cognitive model of transition, which postulates that distress occurs if core assumptions about oneself or the world are threatened by new experiences. The model proposes that when an experience is too painful or incompatible with the individual's expectations, denial is used as a defence mechanism. This prevents the integration of the cancer experience with existing identity coherence or meaning making. Ehlers and Steil (1995) suggested that denial results in a cycle of avoidance and intrusion of distress, until the experience is integrated. Therefore compartmentalising identity roles, withdrawing from situations in which this loss is apparent, enables denial of the loss brought about by cancer but may lead to psychological difficulties in the long-term if the individual is unable to integrate their experiences over time.

Bracketing. Another way to understand the compartmentalisation described by participants is 'bracketing', confining uncertainty to the event that caused it, separating it from the flow of life (Husserl, 1970). In this study, bracketing only appeared possible when participants were able to reclaim disrupted identity roles post-treatment, or when participants had an alternative rationale for any identity changes, namely the effects of aging, which enabled continuity and coherence. These alternative explanations allowed some participants to make necessary changes, e.g. focusing on their health, altering or deprioritising identity roles, in a more socially acceptable way.

Limitations of the Current Study

Interpretative phenomenological analysis. In the study all participants mentioned the difficulty of conveying their experience in words. However, all felt that the descriptions captured in the spider-diagrams of their pre- and post-cancer identities sufficiently captured their experience. Some participants' accounts were ambivalent, contradictory or lacked coherence. Narrative analysis would have been appropriate for considering temporal coherence in more detail, and ambivalence or contradictions could have been explored in more detail had discourse analysis been used. It was beyond the scope of this paper to consider all of these areas; instead priority was given to the participants' experiences.

Rigour and commitment. My interests in, and understanding of, identity and meaning making will have shaped the development of the interview questions, the exploration of participants' experiences, and the extraction of data and themes.²³ I sought guidance from experienced supervisors and key literature, ensuring the study was as rigorous as possible within the limitations of time and resources. I was committed to obtaining a good account of participants' experiences and their understanding, developing skills of engagement and reflecting on my influence within interviews, refining interviewing techniques throughout. Reflexivity was also implemented during analysis, working iteratively; ensuring themes adequately represented excerpts from participants' accounts and keeping a journal of reflections throughout the research process. The methods employed have been clearly described,

²³ See Appendix Q: Reflexivity statement

enabling the reader to judge the quality of the study for themselves. Claims made have been based within wider research evidence and existing theories and contradictory findings have been considered.

Recruitment. All participants were recruited from one hospital and treated at a similar time. There was a lack of ethnic diversity and single people, and some cancer types were not represented. Also participants chose to take part, which may represent a self-selection bias, including those who are more comfortable being reflective or better able to use social support.

Practical limitations. Participants were not asked for their input at the analysis stage due to time limitations. However, the researcher is in the process of obtaining feedback from participants.

Clinical Implications

These findings suggest that empathic social or clinical support, explicitly helping individuals reconstruct their identities and sense of meaning in the post-treatment phase, is likely to be beneficial. Individuals should be given the opportunity to describe their experiences, to talk about how they see themselves, and to come to terms with any losses they might have experienced. This will validate their experiences and help them to make sense of them. It is important for the individual to be given the chance to talk about what is meaningful to them, helping them to re-claim and renegotiate disrupted identity roles in a meaningful way. It may be useful to help the individual to identify specific, attainable, meaningful goals which they can focus on and work towards.

For individuals who have ongoing difficulties, more complex psychological therapies for which there is some evidence of effectiveness with cancer patients

may be helpful. Examples include adjuvant psychological therapy (Greer & Moorey, 1997), helping to re-establish a coherent identity and sense of meaning, and positive psychology interventions (Casellas-Grau, Font, & Vives, 2014), promoting meaning and transforming or overcoming more negative aspects.

The denial, or bracketing, of cancer experiences may for some individuals result in on-going psychological distress, such as frustration or low mood. Psychological interventions targeting defence mechanisms may be effective for individuals experiencing these difficulties, such as Short Term Psychodynamic Psychotherapy (Beutel et al., 2014).

Conclusion

All participants experienced a disruption of identity coherence as a result of cancer, causing uncertainty for all and frustration or low mood for some. For some the disruption was only temporary, and regaining and redefining identity role repertoires restored coherence. However, for others it was not possible to reclaim identity roles, resulting in a need to renegotiate valued identity roles. Recommendations were made as to how clinical practice could support individuals in light of these findings.

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Appendices

Appendix F: Approval from Frenchay Research Ethics Committee, NHS Health Research Authority



Health Research Authority

NRES Committee South West - Frenchay

Bristol Research Ethics Committee Centre
Level 3, Block B
Whitefriars
Lewins Mead,
Bristol
BS1 2NT

Telephone: 01173421334
Facsimile: 01173420445

28 June 2013

Ms Sarah Masson
Trainee Clinical Psychologist
Taunton and Somerset NHS Foundation Trust
Clinical Psychology Doctorate
Washington Singer Building
University of Exeter, Perry Road
EX4 4QG

Dear Ms Masson

Study title:	Identity and Meaning Making in the Post-Treatment Phase of Cancer
REC reference:	13/SW/0138
Protocol number:	n/a
IRAS project ID:	122338

The Research Ethics Committee reviewed the above application at the meeting held on 14 June 2013. Thank you for attending to discuss the application.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Co-ordinator Miss Christine Hobson, nrescommittee.southwest-frenchay@nhs.net.

Ethical opinion: Favourable with Conditions

1. The Committee requested further clarification of the recruitment process as the submission referred to participants being contacted by telephone.

You clarified that the first approach would be in the clinic where the patient would give verbal permission for their contact details to be given to the research team. You confirmed that if this information was not recorded in the clinic, the clinic team would contact the patient by telephone to agree that their details could be passed on. You explained that the purposive sampling would

be based on the details from the information form to ensure that patients with different types of cancer were included in the study.

The Committee considered this explanation and agreed that a 'Permission to Contact' slip should be initialled by the participant at the clinic rather than contacting them by telephone if their permission had not been recorded.

2. The Committee questioned whether the supervisor would be present during the interviews and expressed concern that you might not be experienced enough to administer interviews on such an emotive topic. The Committee requested reassurance of your experience of working with terminally ill patients.

You confirmed that your supervisor would not be present during the interviews but that the participants could be referred to your supervisor if they required extra support. You explained that if a participant became distressed you would put the interview on hold and would refer them to the relevant help. You highlighted that you were used to working with people who might be emotionally upset and that you had completed a six month placement in a hospice working with terminally ill patients.

The Committee was satisfied with this clarification.

3. The Committee expressed concern that using the prompts relating to identity could lead participants' thoughts and bias the findings.

You clarified that the amount of prompting would depend on the person and the prompts would be used discretionally to help people to think on a personal basis. You confirmed that the list of words would be shown at the beginning of the interview and then taken away, and the list had been compiled to use a diverse range of words from the literature. You stated that the prompts should not affect the outcomes as the analysis (IPA) worked by acknowledging the participants experience and taking account their interpretation. You asserted that you had originally shared the same concerns about using the list however; it was implemented following a review by the Thames Valley Research Network which comprised of a cancer specific group.

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Ethical review of research sites

NHS Sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

1. Please ask participants to initial a 'Permission to Contact' slip in the clinic rather than contacting them by telephone afterwards.
2. The PIS should specify that an external company would be used to transcribe the data but that none of the information would be identifiable.
3. Please amend page 3 of the PIS to state that the project was reviewed and given a favourable opinion by the Frenchay Research Ethics Committee.

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

It is responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The documents reviewed and approved at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering Letter		09 May 2013
Evidence of insurance or indemnity		01 August 2012
Evidence of insurance or indemnity		13 July 2012
GP/Consultant Information Sheets	1	28 September 2012
Interview Schedules/Topic Guides	1	28 September 2013
Investigator CV		

Letter from Sponsor		08 May 2013
Letter of invitation to participant	1	28 September 2012
Other: Supervisor Smithson CV		
Other: Information form to be completed by Clinician	1	28 April 2013
Other: Anna Lagerdahl CV		
Other: Devon Transcription Data Protection Information		
Other: Telephone script for researcher		
Participant Consent Form	1	28 September 2012
Protocol	1	04 December 2012
REC application		09 May 2013
Referees or other scientific critique report		
Summary/Synopsis	1	28 April 2013

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

There were no declarations of interest.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

13/SW/0138

Please quote this number on all correspondence

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

With the Committee's best wishes for the success of this project.

Yours sincerely



Dr Robert Beetham
Chair

Email: nrescommittee.southwest-frenchay@nhs.net

Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments

"After ethical review – guidance for researchers"

*Copy to: G M Seymour
Ms Debbie Palmer, [REDACTED] NHS Foundation Trust*

Appendix G: NHS Health Research Authority Acknowledgement of Conditional Documents



Telephone: 0117 342 1335
Facsimile: 0117 342 0445

19 July 2013

Ms Sarah Masson
Trainee Clinical Psychologist
Taunton and Somerset NHS Foundation Trust
Clinical Psychology Doctorate
Washington Singer Building
University of Exeter, Perry Road
EX4 4QG

Dear Ms Masson

Study title: Identity and Meaning Making in the Post-Treatment
Phase of Cancer
REC reference: 13/SW/0138
Protocol number: n/a
IRAS project ID: 122338

Thank you for your letter of 14th July 2013. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 28 June 2013

Documents received

The documents received were as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Other: Permission to Contact Slip for Potential Participants	2	12 July 2013
Other: Response to Committee		14 July 2013
Participant Consent Form	2	12 July 2013
Participant Information Sheet	2	12 July 2013
Protocol	2	12 July 2013

Approved documents

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

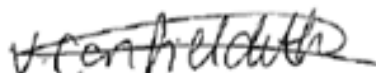
<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering Letter		09 May 2013
Evidence of insurance or indemnity		01 August 2012
Evidence of insurance or indemnity		13 July 2012
GP/Consultant Information Sheets	1	28 September 2012
Interview Schedules/Topic Guides	1	28 September 2013
Investigator CV		
Letter from Sponsor		08 May 2013
Letter of invitation to participant	1	28 September 2012
Other: Supervisor Smithson CV		
Other: Information form to be completed by Clinician	1	28 April 2013
Other: Anna Lagerdahl CV		
Other: Devon Transcription Data Protection Information		
Other: Telephone script for researcher		
Other: Permission to Contact Slip for Potential Participants	2	12 July 2013
Other: Response to Committee		14 July 2013
Participant Consent Form	2	12 July 2013
Participant Information Sheet	2	12 July 2013
Protocol	2	12 July 2013
REC application		09 May 2013
Referees or other scientific critique report		
Summary/Synopsis	1	28 April 2013

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

13/SW/0138

Please quote this number on all correspondence

Yours sincerely



Mrs Vicky Canfield-Duthie
Assistant Committee Co-ordinator

E-mail: nrescommittee.southwest-frenchay@nhs.net

Copy to: G M Seymour,
Ms Debbie Palmer, [REDACTED] NHS Foundation Trust

Appendix H: Approval from the University of Exeter Psychology Ethics Committee



Psychology Research Ethics Committee

Psychology, College of Life & Environmental Sciences

Washington Singer Laboratories
Perry Road
Exeter
EX4 4QG

Telephone +44 (0)1392 724611
Fax +44 (0)1392 724623
Email Marilyn.evans@exeter.ac.uk

To: Sarah Masson
From: Cris Burgess
CC: Janet Smithson
Re: Application 2012/557 Ethics Committee
Date: April 4, 2014

The School of Psychology Ethics Committee has now discussed your application, **2012/557 – Identify and meaning making in the post-treatment phase of cancer**. The project has been approved in principle for the duration of your study.

The agreement of the Committee is subject to your compliance with the British Psychological Society Code of Conduct and the University of Exeter procedures for data protection (<http://www.ex.ac.uk/admin/academic/datapro/>). In any correspondence with the Ethics Committee about this application, please quote the reference number above.

I wish you every success with your research.

A handwritten signature in black ink, appearing to read 'Cris Burgess', with a horizontal line underneath.

Cris Burgess
Chair of Psychology Research Ethics Committee

Appendix I: Research and Development Approval from the Participating NHS Foundation Trust

RESEARCH & DEVELOPMENT
Today's Research | Tomorrow's Care

[REDACTED]
NHS Foundation Trust



Research & Development
[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]

18th September 2013

Dr Anna Lagerdahl
Clinical Psychologist

[REDACTED]
[REDACTED]
[REDACTED]

Dear Dr Lagerdahl

Project Title: Identity and Meaning Making in the Post-Treatment Phase of Cancer
REC Reference: 13/SW/0138

[REDACTED] NHS Foundation Trust Research & Development Department (R&D) have assessed the locality issues in respect of the above submission and are able to confirm Trust R&D approval for you to proceed with the above project.

We strongly advise you and other members of your research team to note that Trust approval is conditional upon adherence to the following terms and conditions:

- The study is carried out according to ICH GCP.
- Is conducted within the guidelines of the Research Governance Framework for Health and Social Care 2nd Edition 2005, the Data Protection Act 1998 and the Health & Safety Act 1974 copies of which may be obtained from the following website:
www.doh.gov.uk
- You and your research team adhere to the protocol approved by the Main Research Ethics Committee (MREC).
- All participants sign informed consent (unless not required by the MREC)
- An Investigator Site File is maintained.
- Information concerning safety, monitoring, protocol amendments and outcomes, as well as an annual and completion report are to be provided promptly to the MREC and to the R&D Office.
- The protocol and supporting documents held by the R&D office are the same as those approved by the REC providing up to date versions as and when necessary.
- In the case of an Investigational Medicinal Product (IMP) Study – You and key members of the research team have received ICH GCP training.

Please note that [REDACTED] NHS Foundation Trust is required to monitor research to ensure compliance with the Research Governance Framework and other legal and regulatory requirements. The above research may be selected for audit.

Our Values
Service Teamwork Ambition Respect

Document versions approved:-

DOCUMENT	VERSION	DATE
Protocol	2	12 July 2013
Permission to Contact Slip for Potential Participants	2	12 July 2013
Participant Information Sheet	2	12 July 2013
Participant Consent Form	2	12 July 2013
Invitation Letter to Participant	1	28 September 2012
GP Letter	1	28 September 2012
Interview Schedules/Topic Guides	1	28 September 2012
Summary/Synopsis: Flow chart of procedure	1	28 April 2013

Finally, Good luck with your research, and please contact the R&D department again if you have any further queries.

Yours sincerely



Dr David Collins
Research and Development Director

Cc: Sarah Masson, Trainee Clinical Psychologist, Taunton and Somerset NHS Foundation Trust

Our Values
Service Teamwork Ambition Respect

Appendix J: Participant Information Sheet**Participant Information Sheet****Identity and Meaning Making in the Post-Treatment Phase for Cancer**

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. Please take the time to read this information sheet. Before taking part in the study a researcher will go through this sheet with you and answer any questions you have. We encourage you to talk to others about the study if you wish.

What is the purpose of the study?

We are interested in understanding what impact, if any, cancer has on a person's sense of who they are, as well as thoughts and feelings that a person may have about their existence, their life, their relationship to others, and their place in the world more generally following the end of treatment.

Why have I been invited to take part?

You have been asked to participate because you have received treatment for cancer at the [REDACTED] within the past year, which is where the study is taking place. We hope that fifteen people will participate.

Do I have to take part?

No. It is up to you to decide if you want to take part in the study. If you agree to participate, and later change your mind, you can withdraw without giving a reason up until 31st October 2013, which is when the write up will begin. If you withdraw, any information you have provided will be destroyed. The decisions you make about this research will in no way effect your current or future relationship with NHS services.

What is involved?

If you decide to take part in the study, we will ask you some questions about your experiences of completing cancer treatment in a one off, 60-90 minute interview with a researcher. This interview will take place at the [REDACTED] and will be audio-recorded to aid analysis. You can talk as much or as little as you like about each question. If there are any questions you do not wish to answer just tell the researcher and they will move on to the next question. You will not have to give a reason as to why a question was skipped. You will be encouraged to give your account in a way that is relevant and meaningful for you. The researcher will try to explore your thoughts and feelings about your experiences.

Will any costs incurred as a result of taking part be reimbursed?

Parking costs incurred as a result of participating will be reimbursed.

Are there any risks to participation?

We do not anticipate that there will be any risks to you taking part. However, asking people to think about their experiences may give rise to difficult topics, feelings and memories. The researcher will be sensitive to any signs of possible upset or distress and if necessary, or requested, will offer breaks, rearrange or end the interview.



Should you require it, information will also be provided to you about how to access additional support after the interview has ended.

We don't envisage that the interview will reveal any information of concern regarding harm to you or to others. However, should a disclosure of this nature emerge in the interview, the researchers are duty bound to report this to the relevant agency. This will be discussed with you prior to the interview.

Are there any benefits to participation?

We don't think that the findings of the study will be of any direct benefit to you. However, they are likely to provide a better understanding of your experiences and what is important to you. It is hoped that this information will contribute to the development of future interventions to help support people who go through a similar journey. The findings may also provide recommendations for future research.

Is the study confidential?

Yes. We will follow ethical and legal practice to ensure that all information about you will be handled in confidence. All personal information will be stored in a locked cabinet at the [REDACTED] and disposed of after one year. Only the two main researchers, Sarah Masson and Anna Lagerdahl, will have access to identifiable information. This information will be stored separately from any anonymised data. No personal details will leave [REDACTED] at any time. The interview will be conducted in a confidential setting at the [REDACTED]. All data collected, including the audio-recording and subsequent written transcription, will be securely stored in locked cabinets and destroyed after five years. An external company, Devon transcription, may complete some of the transcriptions. They provide a secure and confidential service and no identifiable personal data will be sent to them. The information you provide will only be accessed by authorised members of the research team and regulatory authorities. The transcription and any quotations used will be completely anonymous. The research team will operate in line with the Data Protection Act (1998).

You have the right to check the accuracy of any data held about you and to correct any errors. At the time of the interview, please let the researcher conducting the interview know, should you wish to view your interview transcript. Any corrections would need to be made before analysis begins, therefore the researcher will let you know when you will need to respond by.

Involvement of your General Practitioner (GP)

We will ask your permission to send a letter to your GP to inform them of your involvement in the study.

How will the findings be used?

The transcripts from the interviews for all the participants will be analysed and common themes will be identified. The results will contribute to the [REDACTED] Oncology and Haematology Department's understanding in this area. It is hoped that a write up of the study will be submitted to academic journals and presented at conferences. The findings will also be written up and submitted to the University of Exeter as part a researcher's thesis for a doctorate in Clinical Psychology. A summary report of the findings will be sent to all participants, unless you choose not to receive this.

**Who is organising the research?**

This research study is being conducted by a Trainee Clinical Psychologist from the University of Exeter in collaboration with [REDACTED] Oncology and Haematology Department.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, known as a Research Ethics Committee, to protect your interests. This study has been reviewed and given a favourable opinion by the Frenchay Research Ethics Committee.

What should I do now?

Please think about whether or not you would like to take part in this research. Talk with others about the study if you wish and feel free to contact us on the contact details below with any questions you may have. A researcher will call you in the next week regarding your potential participation. If you no longer wish to be contacted just let us know using the contact details below.

Further information and contact details

For general information about research please visit:

<http://www.bartsandthelondon.nhs.uk/our-services/research-and-development/about-us/taking-part-in-research-patients-and-public/>

For specific information about this research project or if you have any concerns you can contact:

Sarah Masson
Trainee Clinical Psychologist

Dr Anna Lagerdahl
Clinical Psychologist

Address

[REDACTED]

Tel

[REDACTED]

Thank you for taking the time to consider this study. If you have any questions please do not hesitate to contact us.

Appendix K: The Consent Form



Patient Identification Number for this study: _____

PARTICIPANT CONSENT FORM

Title of Project: Identity and Meaning Making in the Post-Treatment Phase for Cancer.

Name of Researchers: Sarah Masson and Dr Anna Lagerdahl

Thank you for taking part in this research.

The following statements relate to the above named study and the information that you were given in the participant information sheet. Please read each of the following statements carefully and initial the boxes next to them to confirm that you agree:

Please initial the b

1. I confirm that I have read and understand the information sheet (dated 12.07.13, version 2) for the above study.
2. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
3. I understand that my participation is voluntary and that I am free to withdraw from the study at any time prior to the beginning of analysis (31st October 2013) without having to give a reason and without my healthcare being affected in any way.
4. I understand that the interview will be audio-recorded and later transcribed for data analysis purposes.
5. I agree to my GP (and/or other health or care professionals responsible for my care) being informed of my participation in this research.
Please initial the appropriate box **Yes** **No**
6. I agree to the use of anonymised, verbatim quotations from my interview.
7. I agree to take part in the above study.

Name of Participant

Date

Signature

Name of Researcher

Date

Signature

If you do not wish to receive a summary report of the findings please tick here.

Appendix L: Letter Informing GP of Participant's Participation in the Study



Oncology and Haematology Department



Date:

Dear *[Name of GP]*,

We are writing to inform you that *[Name of participant]* has agreed to participate in a research project exploring what impact cancer has on a person's sense of identity and meaning making following the end of treatment with curative intent.

The project consists of a one-off interview, last approximately one hour, asking about *{Participant's first name}'s* experiences.

If you would like more information about this study please do not hesitate to contact us.

Yours sincerely,

Sarah Masson & Dr Anna Lagerdahl
The Research Team

Appendix M: Dissemination Statement

A summary report will be sent to all participants, as well as interested clinicians and professionals from the participating NHS trust and to the local TVCRN CRP group. The research will be presented at a research event at the University of Exeter for colleagues and other interested parties. It is planned that the study will be written-up for publication in the Journal of Cancer Survivorship and opportunities to present the findings at relevant conferences and research events will be explored.

Appendix N: Semi-Structured Interview Schedule



Interview Schedule

➤ *Interviewer introduces themselves*

- “My name is Sarah Masson, I am one of the researchers for the study.”

“I have a few key points to go through before we begin the interview to check that you are fully informed about the project and happy to go ahead”

➤ *Introduction to the interview*

- “Thank you for agreeing to take part in this interview. It should take between one to one and a half hours.”
- “If at any time you would like to stop, take a break leave or similar, please let me know and we will stop immediately.”

➤ *Participant information sheet*

- “Have you had time to read and understand the information sheet? I will briefly summarise the main points:
 - The interview is confidential. Your clinical team and GP will know that you have participated, but only the research team will know what you have said. However, if any information you provide identifies significant risk to yourself or others I will have a duty of care to inform the relevant agency in order to keep yourself and others as safe as possible.
 - I’ll be recording the session, this is just to make sure that I record the information you give me accurately.
 - All information will be stored in locked filing cabinets in the cancer service office. Your personal information will be stored for one year, separate from the anonymised interview data, which will be stored for five years.
 - Quotes from your interview may be used. However, your name and any names you mention will be removed.



- Before 20th December 2013 you can withdraw from the study without giving a reason. All information you have provided will be destroyed. It will not be possible to withdraw after this date as the study will have been written-up.
 - Do you have any questions?
 - Also, feel free to ask questions during the interview if you need any clarification.”
- ***Explanation about how the interview data may be used***
- “The information you give us today will help us to better understand your experiences. It is hoped that this information will help us to better understand how to support people who go through a similar journey.”
- ***Explanation about the interview boundaries***
- “I am particularly interested in understanding what impact Cancer has had, if any, on your sense of identity, who you are, and how you make meaning of life and your experiences, your sense of purpose. I may at times bring us back to this specific topic to help us stay focused. Are you happy with this?”
- ***Obtaining consent***
- “Now that we have gone through all these things can I just confirm that you are you happy to take part in the interview and for the information you share to be used and published as part of a research project?”

If no “Thank you for your time” and end the appointment.

If yes “Please read and complete the consent form which we will keep securely for our records.”

Go through the consent form with the individual and answer any questions they might have.

“To start, here is a list of words commonly used to describe a person’s identity. This list is an example, not all of the words will apply to you and you may have additional words to describe who you are that are not on the list.” *Show them the list of words. Give them time to read it.* Also, here is a



blank example of a spider diagram. We will be creating these to help me gain a better understanding of the parts you feel make up your identity.” *Show them the blank spider-diagram. Give them time to look at it. Remove both the list and blank example before starting the interview.*

“Ok I’m going to start recording now. To preserve confidentiality, I will not use your name once the recording starts... OK?”

The interviews are considered to be narrative interviews, i.e. questions and supplementary questions should be “open-ended” in order to invite participants to talk freely about different themes as they tell their stories. The way in which the following issues will be addressed cannot be predicted and are likely to be different across interviews, reflecting the idea that participants will have different stories to tell.

Participants will be asked to draw a spider-diagram of their pre- and post-cancer identities. This is to facilitate the communication of the complex concept of identity and to act as a reference for later accounts. Paper and pens will be provided. The interviewer starts the spider-diagram off and adds a few identities mentioned by the participant. The interviewer will give the diagram to the participant to amend and add to it.

Interview

- **“With the list that I showed you in mind, think back to 6 months before you received your cancer diagnosis. What words would you use to describe yourself, your identity, then?”**
 - “What sort of person were you?”
 - “What words would you use to describe yourself/this part of you then?”
 - “What words might others use to describe you then?” – *for any identities they give in response to this question check whether this is how they saw themselves*



“We will now think about how you view yourself now. I will take this drawing away whilst we do this but will bring it back in second.”

- **“What words would you use to describe yourself, your identity, now?”**
 - “What sort of person are you?”
 - “What words would you use to describe yourself/this part of you now?”
 - “What words would others use to describe you now?” –*for any identities they give in response to this question check whether this is how they see themselves*

Interviewer brings back the first diagram.

- **“Looking at these two drawings, what do you notice?”**
 - “What do you notice about who you were before cancer and who you are now?”
 - “How do you feel about this?”
 - “Is anything the same? How?”
 - “Is anything different? How?”
 - “Overall what is the biggest impact cancer has had on your identity?”

If they feel that their identity has changed:

- **–“Why do you think these changes have occurred?”**
 - “How have you found this?”
- **“Has this change in who you are affected how you make sense of things? If so, how?”**
 - “the meaning of your relationships?”
 - “the meaning of your life?”
 - “the meaning of your place in the world?”
 - “the meaning of your existence?”



- The things you value, your purpose or beliefs?

If their meaning has changed:

- **“Why do you think this it is?”**

OPTIONAL

- **“Have you been able to find ways forward after any change in who you are?”**
 - “How have you done this?”
 - “Has this been difficult or easy?”
 - “What has been helpful?”

If they feel that their identity has not changed:

- **“What has helped you to maintain your sense of who you are, your identity?”**
 - Has anything made this difficult or easy?
- **“Has having cancer affected how you make sense of things? If so, how?”**
 - “the meaning of your relationships?”
 - “the meaning of your life?”
 - “the meaning of your place in the world?”
 - “the meaning of your existence?”
 - The things you value, your purpose or beliefs?

If their meaning has changed:

- **“Why do you think this it is?”**

General prompts:

- “Can you tell me more about that?”
- “How do you feel about that?”
- “Could you explain that some more?”

At the end of the interview:

“Thank you for sharing this information with me, is there anything else you would like to add that you may not have remembered to say earlier or that I may not have asked you about your experiences?”



“Is there anything you would like to ask me?”

“You may find that this makes you think about things in a new way. If you would like to talk to someone about this feel free to contact me.”

“Remember that should you feel you need to talk to someone as a result of this interview please contact me on the information provided on the participant information sheet.”

End of interview.

Appendix O: Example of Transcript Coding

Descriptive comments Linguistic comments conceptual comments

R: Yeah. He'd come down and say, "Mummy, it's raining in the kitchen." "Hey?" But he'd get up to mischievous things.

I: He was curious, yes.

R: Yes.

I: And in terms of how you saw yourself before, does that feel like it's captured it? Does it feel like that's kind of...? You know, do you feel comfortable that that kind of gives it the quick overview of the key points?

R: Yeah.

I: And if we think about after, so now how you see yourself, what words would you use to describe yourself?

R: Well, if I completely forget about what happened last year I'm back to where I was before.

I: Hmm. So it feels very much the same. These still apply?

R: Yeah.

I: So if I put these back on. So if I start with, kind of, fun-loving.

R: Just a bit older and a bit crankier.

I: So if you think about fun-loving, have you noticed anything that's changed, or is it the same? What have you noticed with that part?

R: Not really. The only thing I think you become more aware of is who your real friends are, and all my, sort of, like, old loyal friends have all remained loyal friends. But the new ones that perhaps weren't my original friends or, sort of, like, friends of people I have met here, friends of my husband... I have been slightly disappointed that some of the friends of my husband weren't loyal friends like I have got. I'd say, "Look, just keep an eye on him while I'm in hospital," or whatever. Whereas I'd know if I was in [redacted] all my friends would be round there, cooking for him, washing up, washing dishes, "Go and see her." If you need anything, they'll be there. Whereas his mates here, sort of, like, "Come and have a drink. Play darts with us." They weren't there at all. They weren't very supportive. So in a sense of, sort of, like... In some ways you think why am I in [redacted]? Why am I not back in [redacted] with the good loyal friends who would be better quality friends [laughter]?

Because my husband, I have only been married to him a couple of years. Because I got married just before I got the diagnosis and got the treatment. And he hasn't been fortunate to have a lovely upbringing that I had. He's had quite a struggle. And he could have done with some really good loyal friends. And his so-called close mates here weren't very supportive.

I: That massively highlights the difference, I suppose, considering the importance of your support network and that experience of people always being there and vice versa.

Avoidance? desire or external expectation to forget, return to normal?

forgetting what happened

Age as a way of understanding changes, helps forgetting about cancer? more socially acceptable?

splitting between "his friends" and "my old friends" loyal conceptualised as support network helping out rather than social support, diff views? Seems more talking about mates allowing for her rather than being there for him

frustration? label commonly applied to 'old' people older intolerant?

minimise, deny its effect? prior "fun loving" identity role not really engaged with (shift in priorities?) or avoidance? Been let down.

continuity friends pre + post length of time makes it more valid??

focus on split new life with husband vs her old life with friends seems a reflection on her id vs

a changed id adapting her husband's id and it not feeling genuine.

Hard to talk about herself. is she talking about herself or her husband? projection?

Appendix P: The Identified Themes and Participants Who Experienced Them.

Superordinate themes (number of participants)	Participants who experienced this	Themes (number of participants)
1. Disrupted Identity Roles (10)	1,2,3,6,7,8,9,10,11,12 1,2,3,5,6,8,9,10,11,12 1,2,3,6,7,9,11,12 1,2,3,4,6,8,9,10,11,12	1.1 Physically vulnerable (10) 1.2 Sexual, feminine and masculine (8) 1.3 Symptoms and side-effects (10)
2 Highlights what is Important (12)	1,2,3,4,5,6,7,8,9,10,11,12 3,4,5,7,9,10,12 3,4,5,7,9,10,12 1,2,6,8,11	2.1 Back to normal (7) 2.1.i Deprioritise affected roles (7) 2.2 Changed person (5)
3. Focussed on Priorities (12)	1,2,3,4,5,6,7,8,9,10,11,12 1,3,7,8,9,10,11,12 1,2,3,4,5,6,7,8,9,10,11,12 1,2,3,4,5,6,7,8,9,11,12 1,2,3,4,5,6,7,8,9,10,11,12	3.1. Reclaiming societal roles (8) 3.2. Acting out identity roles (12) 3.3. Social comparison (11) 3.4 Identity supported and validated by others (12)
4. Reduced Awareness of Loss and uncertainty (8)	3,4,5,7,8,9,10,11 8,9,10,11 3,5,7,8,9,10,11 1,2,4,5,6,7,8,9,10,11,12	4.1 Compartmentalise & prioritise what you can achieve and control (4) 4.2 Focus on the positives (7) 4.3 Rationalise the change (11)

Appendix Q: Reflexivity Statement

Firstly, I would like to provide a description of myself. I am a 29 year old, married, white British female, completing doctoral training in the South West of England. This study was completed in partial fulfilment of a Doctoral Degree in Clinical Psychology.

I have personal experience of cancer within my family. I lost three grandparents to cancer and my mother-in-law is a survivor of a particularly aggressive form of breast cancer. I have also worked within a cancer service and hospice. I have seen the impact cancer can have on the individual and discussed their experiences with them. I think that these experiences initially attracted me to this area and led me to presume that individuals with cancer will be able to share their experiences, providing greater insight for clinicians. However, I have not personally experienced cancer myself.

I value the individual's experience, and the importance of working collaboratively with individuals at their level of understanding in order to bring about change. I believe that this led to my interest in the interpretative phenomenological approach, enabling me to try to interpret an individual's experience and sense making in order to best address their experience and provide a person-centred intervention. I am interested in a variety of psychological approaches, believing in the importance of selecting the method most appropriate for that client, in a person-centred way. I value psychological approaches to understanding and supporting individuals experiencing distress, leading me to study psychology at a clinical level and motivating me to pursue this line of enquiry, hoping to identify useful avenues for further research, as well as useful insights for clinical staff

I attempted to check my understanding with clients during the interviews, to reduce the chance of false assumption and misunderstanding. I familiarised myself with participants' accounts, by reading and re-reading interview transcripts, checking my interpretations iteratively and trying to immerse myself, empathically in the individual's experience. I believe that it is possible for me to gain an appreciation of the experiences of others, which can be used to inform clinical practice and further research.

Through this experience I have learnt about the complexities of research methodology, particularly the differences in objective and subjective approaches. This has helped me to be mindful of the particular experience of that individual and the importance of the nuanced version of more generalised, objective models and theories. Analysing participants' accounts provided me with an appreciation of the subtle variations in experiences and sense making and how these can impact upon psychological distress and well-being. The process also highlighted a tendency to simplify and summarise accounts, in a way that can lose the essence of what is important to that individual's experience, requiring iterative comparison between the specific data and the more generalised representation, refining the latter to ensure it provides an accurate summary.

I was struck by the richness of the accounts, particularly the inclusion of themes pertinent to the participants but not necessarily to the focus of the study, i.e. identity and meaning making. I found not attending to these other pertinent factors, such as medical issues or the impact of their experiences on loved ones, difficult, especially as it felt that it was important for the participants that these experiences were shared and validated.

Having completed the research I feel that the most important finding is the importance of understanding cancers impact on what the individual values and how they are able to be in the world, to express themselves. It struck me as important that participants were validated and supported by others to be independent and autonomous, able to strive to achieve meaningful goals by whatever means they could.

Appendix R: Instructions for Authors

Journal of Cancer Survivorship Instructions for Authors

Aim and Scope

Cancer survivorship is a worldwide issue; currently, there are 12 million cancer survivors in the US alone. The aim of this multidisciplinary journal is to increase knowledge about cancer survivorship. The journal publishes peer-reviewed papers relevant to improving the understanding, prevention, and management of the multiple areas related to cancer survivorship that can affect quality of care, access to care, longevity, and quality of life. It is a forum for basic research in humans (laboratory or clinical), clinical studies, literature reviews, policy studies, and case studies. Special issues focus on major topics such as cognitive effects, health behaviours, health services, stress, fatigue, international approaches, and work-related issues. Published articles represent a broad range of fields including internal medicine, public health, behavioural medicine, psychology, health economics, biobehavioural mechanisms, and qualitative analyses.

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Submission of a manuscript implies: that the work described has not been published before; that it is not under consideration for publication anywhere else; that its publication has been approved by all co-authors, if any, as well as by the responsible authorities – tacitly or explicitly – at the institute where the work has been carried out. The publisher will not be held legally responsible should there be any claims for compensation.

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Title Page

The title page should include:
The name(s) of the author(s)

A concise and informative title

The affiliation(s) and address(es) of the author(s)

The e-mail address, telephone and fax numbers of the corresponding author

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Please provide a structured abstract of 150 to 250 words which should be divided into the following sections:

Purpose (stating the main purposes and research question)

Methods

Results

Conclusions

Keywords

Please provide 4 to 6 keywords which can be used for indexing purposes.

Manuscripts are typically 15-20 double-spaced typed pages.

Table and figures should be limited to 3-4 total.

If you think your article will be significantly shorter or longer than that average, please include an explanation along with your submission.

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Manuscripts should be submitted in Word.

Use a normal, plain font (e.g., 10-point Times Roman) for text.

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Use the automatic page numbering function to number the pages.

Do not use field functions.

Use tab stops or other commands for indents, not the space bar.

Use the table function, not spreadsheets, to make tables.

Use the equation editor or MathType for equations.

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Manuscripts with mathematical content can also be submitted in LaTeX.

LaTeX macro package (zip, 182 kB)

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Abbreviations should be defined at first mention and used consistently thereafter.

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Footnotes can be used to give additional information, which may include the citation of a reference included in the reference list. They should not consist solely of a reference citation, and they should never include the bibliographic details of a reference. They should also not contain any figures or tables.

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and other statistical data). Footnotes to the title or the authors of the article are not given reference symbols.

Always use footnotes instead of endnotes.

Acknowledgments

Acknowledgments of people, grants, funds, etc. should be placed in a separate section before the reference list. The names of funding organizations should be written in full.

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Please always use internationally accepted signs and symbols for units (SI units).

Please use the standard mathematical notation for formulae, symbols etc.:
Italic for single letters that denote mathematical constants, variables, and unknown quantities

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Bold for vectors, tensors, and matrices.

References

Citation

Reference citations in the text should be identified by numbers in square brackets. Some examples:

Negotiation research spans many disciplines [3].

This result was later contradicted by Becker and Seligman [5].

This effect has been widely studied [1-3, 7].

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The list of references should only include works that are cited in the text and that have been published or accepted for publication. Personal communications and unpublished works should only be mentioned in the text. Do not use footnotes or endnotes as a substitute for a reference list.

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Book

Blenkinsopp A, Paxton P. Symptoms in the pharmacy: a guide to the management of common illness. 3rd ed. Oxford: Blackwell Science; 1998.

Book chapter

Wyllie AH, Kerr JFR, Currie AR. Cell death: the significance of apoptosis. In: Bourne GH, Danielli JF, Jeon KW, editors. *International review of cytology.* London: Academic; 1980. pp. 251–306.

Online document

Doe J. Title of subordinate document. In: The dictionary of substances and their effects. Royal Society of Chemistry. 1999. [http://www.rsc.org/dose/title of subordinate document](http://www.rsc.org/dose/title%20of%20subordinate%20document). Accessed 15 Jan 1999.

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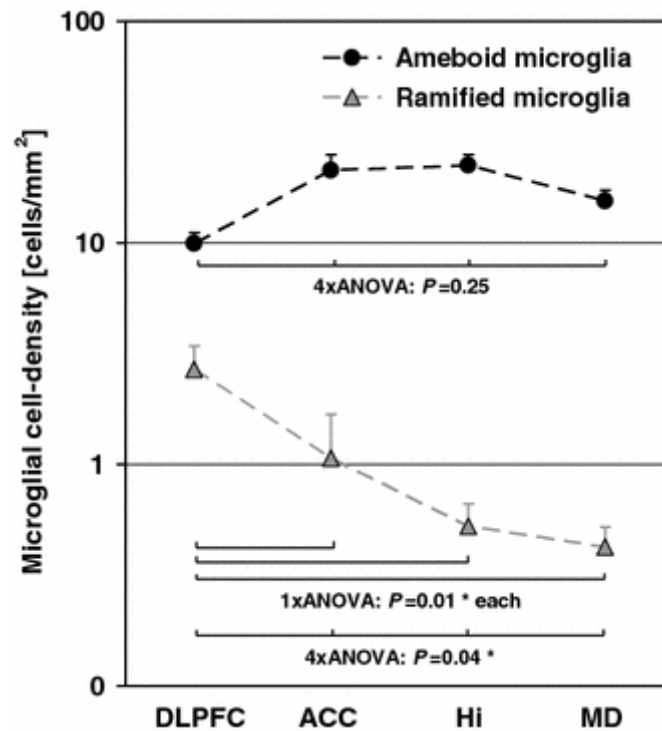
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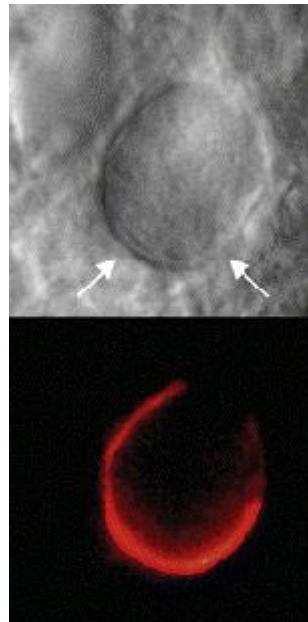
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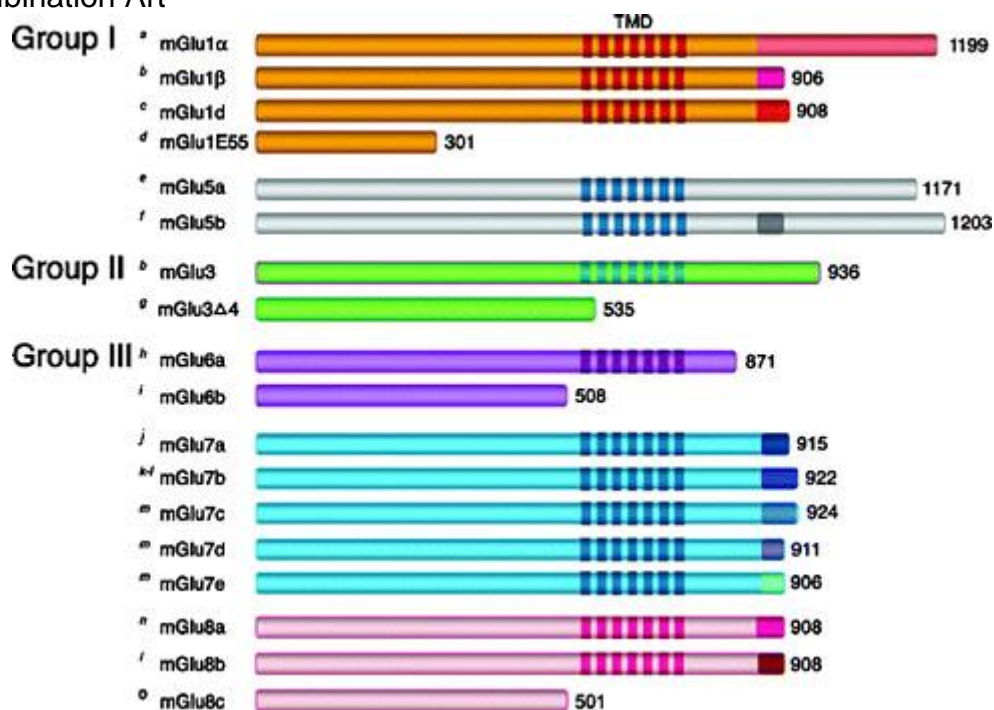


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