

Cancer-related trauma, stigma and growth: the 'lived' experience of head and neck cancer

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Head and neck cancer is associated with multiple layers of distress including stigma. *Stigma attraction* or devalued social identity is twofold: (1) it is a cancer associated with lifestyle risk factors and (2) treatment often results in confronting facial disfigurement. Subjective interpretations from nine head and neck cancer patients were analysed using Interpretative Phenomenological Analysis. An overarching superordinate theme – *Distress, Stigma and Psychological Growth* – encompassed four subordinate themes. Two themes captured the expressed trauma and terror as a result of diagnosis and treatment, and two the redefining of self despite stigma through meaning making. Distress was interpreted as a catalyst for awakening new life interpretations and combined with social support to facilitate two distinct pathways of growth: (1) psychological growth without support; (2) psychological and relational growth with support. Previously unfelt empathetic understanding and altruism for others with cancer emerged from the impact of stigma on 'self'. Acceptance allowed a new sense of identity that recognised cancer-related traumatic distress as integral to growth for these participants. The present study offers a unique insight into cancer-related trauma and stigma and the potential to redefine a more accepting, empathic and altruistic 'self' for psychological growth. Implications are discussed.

Keywords: IPA, stigma, cancer-related trauma, post-traumatic growth.

INTRODUCTION

Dealing with a cancer diagnosis and its associated treatments can be fear-provoking and life-altering. Many report helplessness and/or horror sensing that their life had been threatened as a result of their experience (Cordova *et al.* 2007). In addition to the terrifying shock at diagnosis, each cancer brings with it unique challenges to physical and psychosocial functioning (Stanton 2006). In particular, head and neck cancer patients may be at risk for increased distress (Frampton 2001; Zabora *et al.* 2001; Carlson *et al.*

2004), as life-saving surgical intervention often leave them with significant and visually confronting changes to their facial appearance. Unfortunately, these physical changes may also impact on their functional ability to eat, swallow and speak, resulting in a reduced quality of life. Compounding the distress, disfigurement and disablement can attract unpredictable and even stigmatising responses from others (Macgregor 1990). Despite these known physical and psychosocial consequences, there is a paucity of research exploring the 'lived' experience of head and neck cancer. Therefore, this study will explore both positive and negative subjective interpretations of experiencing head and neck cancer. Through reflective semi-structured interviews, it seeks to understand how these participants have socially constructed, interpreted and made sense of: (1) being diagnosed with head and neck cancer; (2) disfiguring and invasive surgical intervention; and (3) social support and societal responses to this type of cancer.

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Stigma refers to an attribute, visible or non-visible, that identifies the individual as being part of a social category that is undesirable (Jones *et al.* 1984). The bearer of stigma becomes segregated, 'devalued' and 'discredited' (Goffman 1963, p. 3). For those struggling with the aftermath of a cancer diagnosis, cancer-related stigma increases illness burden and can lead to physical, social and psychological morbidity (Peters-Golden 1982; Gamba *et al.* 1992; Fife & Wright 2000). For example, stigma can result in reduced self-esteem (Fife & Wright 2000), is likely to increase isolation and strain social relationships (Peters-Golden 1982), and lead to delayed symptom reporting (Tod *et al.* 2008). These consequences do not independently impact on cancer patients; they are likely to be multifaceted, inter-related and exacerbate each other. Furthermore, given positive social support has been found to assist in helpful coping and recovery in chronic illness (Suls 1982), the effects of stigma pose challenges to a cancer patient's self-concept and recovery.

There are several stigmatising factors that uniquely impact on the aftermath of head and neck cancers. For instance, as the facial region is an important aspect of an individual's identity, changes to facial appearance often cause extreme distress and embarrassment (Macgregor 1990; Fingeret *et al.* 2012). Consequently, body image concerns are highly prevalent among head and neck cancer patients (Fingeret *et al.* 2012). Furthermore, facial disfigurement may impact on an individual's sense of self (Callahan 2005) and well-being (Dropkin 1999) as a visible stigma '... can provide the primary schema through which everything about them is understood' (Crocker *et al.* 1998, p. 507). In fact, facial surgery associated with head and neck cancer has been described as a destruction of self (Turpin *et al.* 2009).

Head and neck cancer has been described as one of the most emotionally traumatic types of cancer (Breitbart & Holland 1988; Dropkin 1989). Those with head and neck cancer face a 'dual burden'; in addition to adjusting to the physical change and debilitation following treatment, treatment itself for head and neck cancer can be particularly distressing, as it has been associated with increased anxiety and significant pain (Dropkin *et al.* 1983; Dropkin 2001). These negative effects can lead to physical and psychosocial impairment. Physically, treatment can cause extreme pain and dryness in mouth and neck areas, impacting on difficulties eating and drinking. Consequently, recovery can be long, resulting in delayed return to work, limited ability to engage in social activities and isolation (Krouse *et al.* 1989). For many, resultant functional debilitations may further exacerbate and prolong psychosocial difficulties by impairing communication,

interfering with social interactions and relationships (Koster & Bergsma 1990) resulting in feelings of isolation and restricting social activities (Gamba *et al.* 1992). Sadly, stigma associated with facial disablement and disfigurement following surgery can add to that emotional distress, impacting on reduced self-esteem, social anxiety, self-consciousness, depression and quality of life (Krouse *et al.* 1989; Devins *et al.* 1994; Clarke 1999).

Beliefs about personal behaviours associated with certain cancers may also impact on feelings of stigmatisation, the trajectory of recovery and sense of self. Lifestyle risk factors associated with head and neck cancers, including alcohol and tobacco consumption (Castellsagué *et al.* 2004), and human papilloma virus (HPV) infection (Herreiro *et al.* 2003), can attract blame and stigma. Yet, research investigating stigma associated with perceived onset controllability among head and neck cancer is very limited (Lebel & Devins 2008). However, there is a growing research base documenting the stigmatisation associated with smoking and lung cancer. Several research studies have reported that lung cancer patients are more stigmatised than individuals diagnosed with other cancer types, because lung cancer is perceived to be a self-inflicted disease (Chapple *et al.* 2004). Among lung cancer patients, this stigma has been found to lead to delayed symptom reporting and increased distress (Raleigh 2010) including feelings of guilt and depression (Kuo & Ma 2002). Behavioural risk factors associated with head and neck cancer, such as alcohol consumption and smoking cigarettes, can elicit blameworthy attributions. As a result, patients are at risk of encountering stigmatising attitudes. Therefore, patients with head and neck cancer are at risk of psychological distress due to both the impact of the cancer diagnosis and its associated stigmatising reactions.

While distress has been associated with poorer functioning (Hegel *et al.* 2008), a growing body of research has documented that it can be the catalyst for psychological growth and personal development and helps explain why some individuals achieve increased psychological well-being after a traumatic event (Joseph & Linley 2005; Joseph 2011; Joseph *et al.* 2012). These individuals find meaning from the event and accommodate trauma-related material in a way that strengthens personal, philosophical and relationship values (Joseph 2011). Understanding how individuals find meaning and develop positive change following cancer diagnosis and treatment is important, given post-traumatic growth has been associated with increased quality of life and protection from depression among breast cancer survivors (Morrill *et al.* 2008).

While post-traumatic growth theory highlights the critical role of positive social support (Ryff 1989; Tedeschi &

Calhoun 1995; Joseph & Linley 2005), recent research suggests that an individual's intrinsic drive to make meaning of distressing events may facilitate a positive redefining of self over time irrespective of positive, and despite negative, external support (McCormack & Joseph 2014). Similarly, a small but burgeoning literature suggests that positive outcomes can occur despite the stigma experienced by head and neck cancer patients (Ruf *et al.* 2009; Thambyrajah *et al.* 2010; Llewellyn *et al.* 2013). In fact, early findings suggest that post-traumatic growth can lessen the negative effect of cancer stigma on psychosocial outcomes (Lebel *et al.* 2013a).

Several aspects of journeying with head and neck cancer are poorly explored. The role of positive social support for psychological growth is posited as necessary (Joseph 2011) suggesting growth is unachievable post-trauma without positive support. Recent studies, however, suggest that growth is possible without support, though delayed (McCormack & Joseph 2013, 2014). Several studies have posited that the relationship between post-traumatic distress and growth following trauma is curvilinear with a critical point for cognitive processing (Butler *et al.*, 2005). Purposeful rumination is said to be the central tenet to that curvilinear relationship and is therefore regarded as key to growth following trauma (Calhoun & Tedesch, 1999; Nolen-Hoeksema & Davis, 2004). How social support impacts on that central tenet is currently unknown.

Similarly, distress, stigma (Peters-Golden 1982; Gamba *et al.* 1992; Fife & Wright 2000) and post-traumatic growth (Lebel, 2013b) are recognised individually in the cancer literature, but little is known regarding subjective interpretations of the co-experience of all three among those who have experienced head and neck cancer. Therefore, using Interpretative Phenomenological Analysis (IPA; Smith 1996), this study aims to add to the extant literature by exploring both positive and negative subjective interpretations of experiencing head and neck cancer. In particular, it seeks to understand how these participants have socially constructed, interpreted and made sense of: (1) being diagnosed with head and neck cancer, (2) experiencing invasive surgical intervention; and (3) social support and societal responses to this type of cancer.

METHOD

Participants

Nine participants, eight male and one female, with a history of head and neck cancer were recruited through nursing referral at a leading teaching hospital in Australia. Participants were eligible if they had been surgically treated for head and neck cancer, which had resulted in

changes to their facial appearance. This was assessed by the Cancer Nurse Coordinator who had many years of experience working with individuals diagnosed and treated for head and neck cancer. All participants had been treated with a neck dissection to remove cancerous areas. Table 1 outlines demographic characteristics of each participant. Pseudonyms are used to protect confidentiality.

Procedure

Following human ethical clearance, participants were sourced through referral from head and neck cancer nurse coordinators, who had been briefed about the project and provided with information regarding eligibility criteria for the study. Participants were subsequently contacted by telephone with information about the study. Study materials including the participant information form, consent form and outline of the semi-structured interview were sent to participants prior to the interview, to help ensure that participants were fully aware of the study's purpose and the material to be covered (Smith *et al.* 2009). The one-on-one interviews were conducted at a time and location most convenient for both parties.

All interviews were audio-recorded using a digital voice recorder and ranged in duration from 40 to 93 min. Participants received a \$25(AUD) gift voucher. The interviews were guided by semi-structured questions, which 'funnelled down' interview material to the topic of interest (Smith & Osborn 2008). The flexible nature of the interviews allowed participants to engage in the double hermeneutics of the dialogue freely and openly, exposing the phenomenon of study interest.

Epistemology

The philosophical underpinnings of the present study rely on phenomenology, critical realism and symbolic interactionism (Denzin 1995). Therefore, it aimed to describe the way in which each participant's world was constructed, interpreted and understood (Spinelli 2005) by allowing the participants to reflectively interpret the immensurable realities of their experience of head and neck cancer (Blaikie 1991). As symbolic interactionism (Blumer, 1969) is the process of interaction in the formation of meanings for individuals, phenomenological studies offer the opportunity for researchers and participants to understand how individuals are influenced by their social interaction, and by the dynamic nature of meaning, which is modified through their interpretation. As the participant's world is always dependent on interpretation of their environment the meaning participants of

Table 1. Participant characteristics

	Age	Gender	Time between surgery and interview (approx.)	Specific Head and Neck cancer	Onset information	Stage	Other treatments
'Shannon'	89	F	9 months	Parotid sweat gland adenocarcinoma	N/A	T1N1M0	Radiotherapy
'James'	72	M	9 months	Squamous cell carcinoma – floor of mouth	Non-viral – participant attributes to smoking	T4N0M0	Radiotherapy
'Kevin'	75	M	6 months	Metastatic squamous cell carcinoma	Non-viral	TxN1Mx	Radiotherapy
'Matt'	57	M	1 year, 2 months	Squamous cell carcinoma – of tongue base	Viral (p16 positive) – participant attributes to HPV	T2N2aM0	Radiotherapy and chemotherapy
'Felix'	42	M	10 months	Squamous cell carcinoma – floor of mouth	Non-viral – participant attributes to smoking	T2N0M0	Radiotherapy and chemotherapy
'Derek'	36	M	1 year, 2 months	Basaloid squamous cell carcinoma – right mandible	Viral (p16 positive) – participant attributes to HPV	T0T2bMx	Radiotherapy, incomplete chemotherapy
'Don'	51	M	3 months	Squamous cell carcinoma – floor of mouth	Non-viral	T2N1M0	Radiotherapy
'Ralph'	56	M	1 month	Squamous cell carcinoma – right neck	Non-viral	TxN2Mx	Radiotherapy and chemotherapy
'Paul'	58	M	2 months	Squamous cell carcinoma – lateral tongue	Non-viral	T1N1Mx	Radiotherapy and chemotherapy

F, female; M, male.

this study ascribed to their experience with head and neck cancer were influenced by the subjective meaning participants brought to them. Relatedly, a critical realist perspective embraces hermeneutic exploration where individuals are constantly finding meaning and interpreting their environment to inform their behaviours (Gadamer 1983). This methodological approach highlights the multiple ways in which an experience can be construed, and moves beyond the discord between objectivism and relativism paradigms (Bernstein 1983). These interpretations fit with both the objectivism stance, which argues that there is only a single valid perspective for meaning making, and the relativism perspective, which contends that there is no absolute truth and that perspectives vary by individual. Through this lens, the study used IPA to analyse the data.

Analysis

Data were collected by use of an audio recording device. Interviews were transcribed verbatim by the first author. Following steps outlined by Smith *et al.* (2009), first, each author independently read and re-read the transcripts, with initial note taking made on the left-hand side; specific font style denoted descriptive, linguistic and conceptual content. Second, material was reviewed independently, incorporating psychological theories and abstractions. These specific themes and short phrases

were placed on the right-hand side of the transcript. Third, each author collated emergent themes that began to develop by identifying the inter-connections and patterns in the exploratory notes. When the procedure was complete for each transcript, the two authors met for robust discussion to agree on convergent and divergent themes. The process was repeated for each transcript. The final stage included developing higher order themes and subthemes across the data set. A step-by-step analysis of the analytic process is provided in Table 2.

Credibility

Rather than provide evidence for inter-reliability and causal relationships often found in quantitative research, the current research employed a detailed audit trail for data review (Smith *et al.* 2009). That is, the audit sought to provide the reader with an account of the data that was analysed in a systematic manner. Data achieved internal coherence, credibility and interpretive rigour, through this detailed audit trail (i.e. raw data, transcripts, notes, diagrams) with robust discussions checking for biases and presuppositions at every level (Smith & Osborn 2008).

The first author conducted and transcribed each of the interviews verbatim. Both authors conducted completely independent analyses of the transcripts. Authors met to review independently reviewed transcripts, during which common themes were checked for authenticity, and inde-

Table 2. Outline of the stages involved in the Interpretative Phenomenological Analysis

Stage	Process
1	Re-listening, verbatim transcription, preparation of first transcript
2	Independent first interpretation by both authors – noting, paraphrasing and summarising the participant's experience; development of emerging themes
3	Robust discussion by authors for credibility of first analysis – thematic development of first transcript to identify meaning making in the face of multiple needs of self and others, distressing experience and cancer stigma
4	Stages 1–3 repeated for eight additional transcripts – identifying convergence and divergence across cases. Clustering of themes that support evidence of subordinate theme
5	Development of overarching theme, 'Distress, Stigma and Psychological Growth'
6	Identification and listing of themes for connectedness
7	Continued assessment of themes and subthemes, including how they related and linked to meaning making, redefining self and well-being
8	Clustering of themes in relation to constructs and theories
9	Data from transcripts reviewed by authors to verify the validity of interpretations from within the text
10	Central theme of 'Distress, Stigma and Psychological Growth' re-assessed
11	Subjective analysis of interpretations for themes representing the phenomenon of the lived experience of head and neck cancer within the context of distress and stigma to develop pathways to personal and relationship growth and well-being
12	Development of narrative by weaving theoretical links to themes with verbatim excerpts from the transcripts
13	Generation of links from several levels of distress and stigma to meaning making and psychological well-being

pendent interpretations were reflected on and robustly debated (Smith *et al.* 2002). Throughout, subsequent communication, reflection of the reiterative and interpretive process and rigorous discussion between authors established a thematic framework supported by rich extracts from the data. A table of convergent and divergent higher order and subthemes was subsequently developed (see Table 3).

Author's perspective

Interpretative Phenomenological Analysis, which involves double hermeneutics, is influenced by the researchers own experiences and preconceptions (Smith 1996). In essence, it is a process of reiterative sense making where the researchers strive to make sense of the participant making sense of their experiences. Through an iterative process, the relationship between each researcher and script was considered to reduce biases, and prevent a major shift in interpretation from the participant's experience and world view to the researchers. Without this, there is the risk that preconceptions and interpretation will be moulded by our own human experience (Heidegger, 1927/1962). Previous experience and knowledge about psycho-oncology and post-trauma reactions challenged the authors to reflect and recognise their own biases and

presuppositions that may have impacted on the interpretation of the data. In the present study, we sought to externalise these preconceptions through reflective practices, independent audit, audit trails and ongoing discussion throughout the analysis.

RESULTS

The following results include the study's thematic outcomes, presented in narrative descriptive analysis. An overarching theme – *Distress, Stigma and Psychological Growth* – encompassed four superordinate themes: (1) Head and neck cancer: trauma trajectory; (2) THIS cancer: stigma and distress; (3) Looking beyond the previous self; and (4) Positive change – self. Two of these themes captured the expressed trauma and terror as a result of diagnosis and treatment whereas themes 3 and 4 captured the redefining of self despite stigma through meaning making. Distress was interpreted as a catalyst for awakening new life interpretations and combined with social support to facilitate two distinct pathways of growth: (1) psychological growth without support; (2) psychological and relational growth with support. Previously unfelt empathetic understanding and altruism for others with cancer emerged from the impact of stigma on 'self'. Acceptance allowed a new sense of identity that recognised cancer-related traumatic distress as integral to growth for these participants. The present study offers a unique insight into cancer-related trauma and stigma and the potential to redefine a more accepting, empathic and altruistic 'self' for psychological growth. The quotations were not chosen based on prevalence within the data, rather they reflect rich evidence from the transcripts.

Table 3. Superordinate theme: distress, stigma and psychological growth overarching subordinate themes

1. Head and neck cancer: trauma trajectory
2. THIS cancer: stigma and distress
3. Looking beyond the previous self
4. Positive change – self

Head and neck cancer: trauma trajectory

Compounding trauma

This theme captures the intensity and multiple layers of distress through diagnosis, treatment and recovery faced by head and neck cancer patients. The fast pace at which they were thrust into an unfamiliar medical system made them feel caught off-guard and vulnerable:

It's extremely confronting ... when you can get into a specialist in 4 hours, you then know you are in trouble. [Matt]

While at the same time, attempts at mentally preparing seemed futile. They were never going to be ready for the journey ahead of them:

It all happened at once. And that was so much to take in ... if I only had a few more months, I'd be prepared but I guess you're never really prepared. [Derek]

Distressing procedures and lengthy recovery times overwhelmed their coping abilities. Cognitive blocking was used as a means to escape and avoid intrusive images associated with losing functional ability to speak and eat, a significant impairment to quality of life:

[With] surgery you could lose ... all of your tongue ... [it] really messes with your head... you're trying to think that one through. [Matt]

Intense feelings of anxiety during the procedures imprinted indelible vivid memories on their consciousness. This meant that physical manifestations of emotional responses to the multiple distressing and traumatic events often unexpectedly overwhelmed them:

I got started again, a few weeks between surgery and radiation ... lots of anxiety ... I was having panic attacks. [Derek]

Terror of collaboration

Although adverse events often occur unexpectedly, medical procedures have their own way of inflicting trauma through complicit consent to the fearful physical invasion of their body. These participants spoke of their panic, horror and fear dealing with the tracheotomy tube. Unable to breathe, handing trust to staff during suctioning of their airway, they felt they had been taken to the brink of life or death:

Absolute panic mode ... I didn't know that they'd suction out my throat and lungs, that I would have

a tube poked down there regularly to suction out the phlegm. You feel like you are choking... the sheer terror. [Felix]

Other highly invasive treatment compounded their distress. The participants spoke of the refinement of medical tools as a symbolic representation of the seriousness of their cancer and the fragility of their life:

At each of these steps you sort of realise that you are getting progressively more seriously into the system and down in terms of all the subtlety of the tools that are being used. [Paul]

Their memories of the event were vivid and extremely distressing. The removal of the tracheostomy tube was a symbol of being handed back control over life. It was a major hurdle and a symbol of recovery.

That was a new lease on life, taking the trachy out – cause that was probably the worst week of my life. [Derek]

'Why me?' versus 'This is it'

'Why me?' was commonly asked for sense making of distressing experiences, particularly among those participants whose lifestyle was healthy prior to diagnosis with cancer. They spoke of feeling punished and undeserving of this fateful narrative:

It was a bit of a shock. Why? I had a healthy lifestyle, why me? ...you do the right thing and you're still punished. [Derek]

Feelings of disconnectedness, a mind struggling to accept a body needing medical intervention, these participants described experiencing shock and disbelief:

I never expected it to happen to me so in some ways it's this out of body experience going on here. [Paul]

However, for older participants there was acceptance, even embracement, of a diagnosis that aligned appropriately with their narrative of life. The three eldest participants, James, Shannon and Kevin recognised the journey they had lived as a long and valuable life, and welcomed cancer as part of their mortality:

Before I went into hospital, I didn't really know whether I would be coming out. And I didn't really ask, but I suppose – I think I would accept what has happened to me. [James]

Some found their own acceptance of cancer was at odds with others' desire to extend their lives. If death was inevitable, they had no desire to extend life:

Once you get to 83 you have had a good life. All I could think at the time was if it is going to happen let it be quick. Don't linger on. [Shannon]

Confronting the unimaginable

Multiple distressing procedures brought raw trauma that overwhelmed all participants. Pragmatic coping statements seemed relevant for distancing anxiety, fear and terror. It was a stopgap that allowed time for more purposeful rumination and reframing:

You are going to treat it as a job ... a really shitty job to do ... we kept on going back to that ... when, you know, we were getting sort of those dark days. [Matt]

Each imagined that other cancer patients were experiencing greater suffering. This allowed distance and a level of detachment from personal multiple and ongoing traumatic experiences:

And you know, I mean there is always someone worse off, as bad as you think things are someone is getting it worse. Yah? It makes you think, all these little things. [Derek]

Having difficulty confronting the unimaginable, some participants required the assistance of a support partner to guide them through their journey. These partners became intimately involved in their experience, to be their eyes and ears to absorb information:

At the bed day-by-day, and having to watch me go through... the nightmare of surgery ... being able to talk to her about it afterwards, debrief. [Felix]

These participants described a dual conflict of sense making. First, their personal narrative of consensual trauma, along with the pain and acceptance of permanent disablement challenged their world view of themselves. Second, unexpected responses from others ingeminated the degree to which their physical identity had changed. Witnessing visible shock in others was an added burden to their unwellcome relationship with cancer. It was as if mortality was reflected back through the expressions of others:

People's reaction ... was confronting ... you could see it in their face, their facial reactions. Like a deer in the headlights ... the word cancer, they think you are going to die. [Derek]

THIS cancer: stigma and distress

Identity struggle

Cumulative upon the fearful experience of undergoing invasive medical procedures, participants were challenged with the permanent aftermath of changes to their facial appearance. Physically, as head and neck cancer participants they became unrecognisable from a previous 'self'. This traumatic journey felt unending as adjusting to a new physical 'self' confronted their sense of former sense:

I wasn't recognised by a very close friend... quite a few actually... that was a bit of a shock. [Derek]

The impact of physical changes was juxtaposed with changes to their personality. Struggling with a dichotomous identity, they had to re-evaluate and redefine who am I. Embarrassed to engage in once common social experiences they recognised a tendency to isolate themselves more than ever:

I feel a bit shut in... I don't want to go out ... if there is a barbeque on I won't go. It is just too hard to constantly explain... why I have got the scars. [Felix]

While medical treatment left these participants physically exhausted, confronting others' furtive stares and learning how to cope with stigmatising reactions took its toll emotionally. Grief and loss persisted throughout the interviews as these participants struggled to reconcile visual changes. Coming to terms with their new appearance was a twisting game of disappointments and lost identity:

The physical, the weight ...were negative impacts ... it still hurts, it really hurts actually, that's what upset me the most. ... I just didn't feel myself. [Derek]

Change to self: a need to belong

While no longer feeling part of their once extended social circles, a sense of inclusion grew among other stigmatised groups. Comfort was experienced, from a shared sense of understanding and struggle to belong again:

Other people with disfigurement or disablement don't even look at me... will give me a nod and that's it. So that's kind of the style of brotherhood or sisterhood ... because they go through the same stigmatism. [Felix]

Close friends and family were seen as integral to adjusting to new 'self'. Looking past the physicality they were able to buffer situations, which enabled processing. By interacting in a way that was consistent with their previous 'self', a slow transition to a new 'self' occurred:

The ones that treat me the same, which I appreciated more because ... they just didn't treat me like I was wrapped in cotton wool, didn't baby me. And that's all you wanted to be, is treated as you were. [Derek]

A deviant past

In addition to the physical stigmatising changes, head and neck cancer patients are confronted with personal lifestyle factors (i.e. alcohol, smoking and HPV infection), which may have made them vulnerable to developing this cancer in the first place. Participants who attributed their cancer onset to past behaviour were regretful of their past and bitter about the consequences.

It's my own stupid fault. I smoked for 28 years ... smoking causes my cancer' [Felix]

Secrecy and invisibility were maintained by many as if holding onto a deep regret about their role in developing cancer. Privately, they acknowledged their own contribution to developing this feared illness, often perceived to develop by unlucky chance. However, fear of rejection and abandonment struggled with feelings of self-blame and guilt:

I suppose sexually transmitted infections, or diseases, that's something we left out quite a lot...there is such a stigma attached. [Derek]

They sensed a wide-spread stigma associated with a blameworthy cancer. For some, self blame was expressed as underserving of the level of compassion afforded other cancers. Feeling shunned they sensed a general lack of support was associated with stigma. Quietly, they felt anger and a sense of injustice:

There is just no information available no level of support for us at all...because its head and neck cancer, it's not popular... because its smoking related... it's not a poster-boy cancer. [Felix]

Looking beyond previous self

Awakenings

Confronting the possibility of an early death, there were moments that could be described as awakenings for these

participants. Their future was now on a different and unfamiliar journey:

You've sort of confronting something that's released a lot of um... inhibition or things you'd always sort of and grown up and been part of you. [Matt]

Uncertainty about the future and fragility of life brought a focus to what is most important to them. This was experienced differently for participants whether they had approached their journey with independence and stoicism, or had become vulnerable and reliant on their family. While the former had developed a sense of focusing on personal insight and growth:

It's a wakeup call that you're not going to live forever. I have a long list of things I want to do... that was always vaguely in the future but I'm thinking now I should just do them. [Paul]

The latter had become more engaged in building stronger meaningful relationships:

This focuses the mind more, at looking at things you value more in life ... like your family and relationships... you've only got them for a finite time so you should make the most interactions with them. [Ralph]

Those, however, who had accepted cancer as a part of their narrative in life, had embraced these changes and came to a humbled understanding of their place and impact in the world.

It's one day at a time, I can't alter the world now. [Shannon]

Positive change – self

Empathetic understanding

In the struggle to understand new 'self', a greater sense of compassion emerged in the participants. Personal adversities and an empathic understanding of others was described, enabling these participants to communicate more effectively and meaningfully. Their journey with cancer brought unexpected positive changes to their life perspectives and an openness not previously experienced in their close relationships:

I have become close to them...I find it easier to talk to them [his children]. Not that it was hard, but... in a different style. You know? [Matt]

These participants expressed a change in interpretation of life from their struggle with 'self' on this journey.

Experiencing unexpected stigma despite their personal suffering, they began to find a new acceptance of others. Redefining self through a stigmatising cancer became the catalyst for increased understanding and a new insider's perspective:

I now see people with either, illnesses or disabilities and I'm a lot more understanding of what they are ... until you go through it – I don't think you sort of appreciate. [Matt]

Altruism

The uniqueness of the head and neck cancer journey and the invasive procedures that terrorised the patients, paradoxically facilitated a desire to help others. Consciously, their personal experience of stigma while at their most vulnerable appeared to facilitate a growth in altruism. Defining a new altruistic identity became a vehicle for personal acceptance allowing others in turn to accept:

This cancer, you can't hide it, you can't sort of put a great big hat on or cover half your face ... where many other cancers you wouldn't know, you don't have the visual impact. ... so in one way, it helps you to help other people too. [Kevin]

Having positive support from a partner appeared interwoven with this increased desire to help others. As vanguards, these supportive loved appeared to enable participants to re-integrate into society:

I often wonder what would happen if I was here by myself and [my wife] wasn't here; how different it would have been. ... because I would then, by nature would have hidden away. [Kevin]

Endurance was made more possible through positive partner support allowing empathy and support of others to be projected forward. Passing on optimism to others starting the journey with head and neck cancer became important. Head and neck cancer was perceived as bringing both positive and negative outcomes inclusive of psychological well-being and a new purpose in life:

I am going to share it [my experience] with people. ... if what I've got can help people, then I am very happy. [Matt]

DISCUSSION

This study highlighted cancer-related traumatic distress and stigma in these participants as a result of dealing with

head and neck cancer. However, despite this distress, positive changes emerged from finding meaning of the stigma and traumatic distress. The participants expressed experiencing trauma and terror as a result of diagnosis and treatment, and unexpected stigma from society as a result of their particular cancer. Over time however, distress became a catalyst for awakening new life interpretations and psychological growth to varying degrees with these participants. Sometimes, this occurred with positive social support and sometimes without support. When support was present, relational growth appeared to be experienced. For all participants, previously unfelt empathetic understanding and altruism for others with cancer emerged from the impact of stigma on 'self'. Similarly, acceptance allowed psychological well-being to emerge out of their experience with cancer-related traumatic distress.

The present study offers a unique insight into cancer-related trauma and stigma and the potential to redefine a more accepting, empathic and altruistic 'self' for psychological growth. By shedding light on the relatively unexplored influence of stigma on psychological growth, within a relevant and understudied population, the current findings can be used to inform hypotheses for future idiographic and nomothetic research. Implications are discussed.

For these participants, psychological growth was experienced differently, depending on social support. Psychological growth was reported among participants without social support; on the other hand, psychological and relationship growth was described among those with social support. Importantly, with or without support, these participants experienced positive change as a result of their exposure to cancer-related trauma and stigma which supports earlier studies recognising that with or without support, post-traumatic growth can occur (McCormack *et al.* 2011; McCormack & Joseph 2013, 2014).

Psychological growth was described among individuals who had approached their cancer journey with independence and stoicism. This domain of post-traumatic growth is defined as becoming more compassionate, gaining wisdom and discovering inner strength (Joseph 2011). For participants in the present study, psychological growth developed as a result of finding inner strength in the face of cancer-related distress and stigma, by redefining their lives through purposeful reflection and engaging in valued activities and experiences. Participants found meaning from their lone journey by creating a new personal narrative. While social support has been found to increase positive adjustment with chronic illness (Suls 1982), here, independence and the need to rely on their own abilities and inner strength to cope led to increased confidence. This new found sense of strength and wisdom was a turn-

ing point, facilitating personal growth. The current findings support previous qualitative (McCormack & Joseph 2014) and quantitative (Widows *et al.* 2000; Weiss 2004) research which found that post-traumatic growth is not dependent on social support. Indeed, individuals are innately driven towards growth, in the pursuit of increased well-being (Joseph & Linley 2005). In the present study, developing their sense of self and actively taking time to live out their own dreams, such as accomplishing their 'bucket list', was put at the forefront of their priorities to improve greater life satisfaction and fulfilment. Relying on themselves through their journey offered a period of self-discovery, where participants' increased their own psychological well-being through self-acceptance, inner strength, autonomy and redefining their purpose in life.

Participants who had become dependent on family for support additionally reported increased growth in their relationships. This was represented by an increased appreciation for significant others. Meaning making from their cancer experience and distress was found to develop from their social support. On their journey, support partners were able to facilitate the participants' needs, aiding them in treatment and recovery. While most core beliefs about themselves and the world had been disrupted as a result of cancer (Holland & Reznik 2005), the availability of positive social support validated that they were loved and cared for, enabling them to find meaning (Silver & Wortman 1980). As such, their distressing experiences had been interpreted as a catalyst for illuminating their important relational bonds. Participants identified they had changed their lives by making more time for loved ones, valuing and appreciating that time, thereby improving the quality of interactions with them. Therefore, the cancer journey brought with it a realisation that life is finite, and redefined purpose in life by strengthening relationships.

While cancer diagnosis and treatments was distressing, which increased awareness of what is important in life, head and neck treatment brought with it stigmatisation that also increased distress. For example, facial changes following surgery resulted in a visible stigma that was not able to be concealed. As one participant noted: 'this cancer, you can't hide it, you can't sort of put a great big hat on or cover half your face'. The visibility of their facial changes made participants vulnerable to stigmatising reactions from others. These responses became internalised, impacting on their self-concept (Livingston & Boyd 2010). The present results highlighted the persistent and intense feelings of grief, loss and ongoing distress regarding the visual changes.

Prior research reporting the distressing and deleterious effects of facial disfigurement, including stigmatising responses from the public (Hagedoorn & Molleman 2006), strained social relationships and subsequent social isolation (Myers *et al.* 1999), is supported in the present results. Consequently, participants reported significant distress in regards to their facial changes, and struggled to redefine who they were. What these participants uniquely experienced was that through active self-discovery and self-acceptance, they were able to move towards positive transformation. Cognitive processing involved making meaning from the societal stigmatisation and forced new identity through the development of a personal narrative. As a result of their traumatic and stigmatising head and neck cancer journey, and their struggle through this experience, growth was seen in increased altruism and empathetic understanding. While these post-traumatic growth domains are not currently captured in measures assessing psychological growth, the phenomenological interpretation of these findings supports previous qualitative research, which has also documented these domains of growth (McCormack & Joseph 2014).

The results suggest that by finding meaning from the stigma, participants had developed a new sense of purpose in life to help and understand others. The capacity to see beyond their physical identity lead to a sense of self-acceptance. In turn, participants felt more accepted by others. Consequently, participants found new meaning in their lives, by self and other acceptance and personal growth through self-discovery. Therefore, while stigmatisation can lead to discrimination and prejudice, reducing quality of life (Fingeret *et al.* 2012), straining social relationships (Macgregor 1990), the present findings highlight that this distress can facilitate personal meaning making and psychological growth.

LIMITATIONS

The present findings should be considered in the light of study limitations. Using an interpretative approach, results are open to the subjective biases as a result of the researchers own self-world, encompassing personal experiences and understandings. However, study methodologies were employed to illuminate biases and presuppositions, which involved completely independent audits and robust discussion.

While quantitative research strives to recruit a sample which would allow for generalisability of results, qualitative research, and IPA in particular, seeks a homogenous cohort for in-depth, subjective exploration by individuals who have experienced a unique phenomenon previously

unexplored. The current findings contribute to the literature on distress, growth and stigma, and provide direction for future qualitative and quantitative research.

CONCLUSIONS

These findings provide further insight into cancer-related traumatic distress and stigma, uniquely specific to head and neck cancer. Similar to earlier studies, the participants felt stigmatised adding to their burden of trauma, fear and loss of self-esteem (Peters-Golden 1982; Gamba *et al.* 1992; Fife & Wright 2000). Socially they felt ostracised, isolated and struggled to recognise supportive social relationships (Peters-Golden 1982). When positive support was forthcoming, they honoured it as helping them to cope with the difficult challenges of this protracted journey (Suls 1982).

These participants' traumatic responses mirrored the dual burden of physical debilitation and fear of treatment described in other studies (Breitbart & Holland 1988; Dropkin 1989). They similarly described the distress asso-

ciated with medical procedures and the ongoing psychosocial impact of other stigmatising factors relevant to the head and neck cancer experience.

Importantly, this study raises awareness that psychological growth is possible from the stigmatising and complex physical and psychological journey with head and neck cancer. For these participants, a positive redefinition of self, evolved over time and was enhanced by positive support. Similarly, these findings offer hope to health care professionals that positive psychological growth is possible despite cancer-related trauma and stigma associated with head and neck cancer and with facial changes following surgery. As a qualitative study, it offers hypotheses for future nomothetic research. Nonetheless, in a therapeutic framework this study emphasises the importance of providing space for head and neck patients to elicit a narrative that explores the likelihood that trauma psychopathology and growth may co-exist. Equally, therapeutic intervention can provide a positive framework for growth out of traumatic distress.

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