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Ceara Clarke, Noleen K. Mccorry and Martin Dempster

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The Role of Identity in Adjustment among Survivors of Oesophageal Cancer

CEARA CLARKE

Northern Health & Social Care Trust, Northern Ireland, UK

NOLEEN K. MCCORRY & MARTIN DEMPSTER

Queen's University Belfast, Northern Ireland, UK



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Abstract

The study sought to contextualize the physical, social and emotional adjustments that are faced by oesophageal cancer patients following surgery. Semi-structured interviews were conducted with five survivors, guided by the principles of Interpretative Phenomenological Analysis (IPA). Participants' accounts encompassed descriptions of personal, social and medical relationships, illness and treatment experiences, eating behaviours, and spiritual and religious perspectives, representing myriad challenges to the self-concept. Surviving patients may have a role in addressing patient expectations about eating. The importance of attempts to nurture and maintain a sense of self should be recognized by those providing care.

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ADDRESS. Correspondence should be directed to:
NOLEEN MCCORRY, School of Psychology, Queen's University Belfast,
Belfast, BT7 1NN, Northern Ireland, UK. [email: n.mccorry@qub.ac.uk]

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- *Interpretative Phenomenological Analysis*
- *oesophageal*
- *survivors*

EVERY YEAR, approximately 7800 people are diagnosed with oesophageal cancer in the United Kingdom (Cancer Research UK, 2010). Surgery is the standard treatment for oesophageal cancer, often combined with adjuvant therapy. On average, two and five year survival rates for oesophageal cancer are 21 per cent and 18 per cent respectively, although survival has been improving (Sundelof, Ye, Dickman, & Lagergren, 2002). For oesophageal cancer survivors (following surgery) quality of life can be reduced (Lindars, 1994; McLarty et al., 1997) as a result of physical symptoms such as eating problems, reflux, cough, oesophageal pain, dry mouth, dysphagia and problems with taste (Viklund, Wengstrom, Rouvelas, Lindblad, & Lagergren, 2006). However, the quantitative measurement of outcomes such as quality of life is an inadequate description of the lived experience of this life threatening disease, and has limited utility for helping to appreciate the meanings associated with these physical symptoms for emotional, psychological or social functioning and adjustment. It is also important to explore process in addition to outcome in adjustment (Thompson, Kent, & Smith, 2002). More recently, the cancer patient has become increasingly central to the research issue, and patient narratives are beginning to occupy a prominent position in research (particularly in breast cancer) because of growing appreciation of their relevance in identifying and meeting the needs of those affected by cancer particularly in the development of services (Cristancho, Garces, Peters, & Mueller, 2008; Lende & Lachiondo, 2009), addressing the burden of illness (Ching, Martinson, & Wong, 2009; Kelly, 2009; Tritter & Calnan, 2002), as well as understanding professional, cultural and societal responses to cancer (Crouch & McKenzie, 2000; Kaiser, 2008; Mathieson & Stam, 1995). There has also been increased recognition of the *utility* of qualitative health research findings in general (Sandelowski, 2004). Oesophageal cancer however, unlike breast cancer, where there is a high level of public engagement (Kaiser, 2008; King, 2006) is not well understood by the public and hence, oesophageal cancer patients remain a somewhat marginalized group. In addition, although cancers are similar in terms of the basic characteristic process of uncontrolled replication at cellular level, there is much variability in the incidence, mortality and treatment of different cancers, and each has its own unique presentation of difficulties (Vickery, Latchford, Hewison, Bellew, & Feber, 2003). It is therefore important to contextualize the challenges faced by

specific patient groups. There have been only a few qualitative investigations from the oesophageal cancer patients' perspective, and these have been quite specific in nature: for example Watt and Wyatt (2003) explored the experience of dysphagia from the perspective of the patient; Mills and Sullivan (2000) described patients' information needs; and Andreassen, Randers, Naslund, Stockeld and Mattiasson (2006) explored how patients seek information. In addition, Wainwright, Donovan, Kavadas, Cramer and Blazeby (2007) have now highlighted the complex interaction of physiological, psychological and social processes involved in 'Remapping the Body' after surgery for oesophageal cancer.

The current study sought to contextualize within this group, the broad physical, social and emotional adjustments that are faced by cancer patients, and to explore in detail the processes through which oesophageal cancer survivors make sense of their experiences. Experiences in this sense include, and are shaped by beliefs, emotions and expectations. We were particularly interested in understanding patients' perceptions and interpretations of their bodily experiences, the meanings they assign to them (Leventhal, Nerenz, & Steele, 1984) and the impact of these on psychological processes of adjustment.

Method

Participants and recruitment

Ethics approval was obtained from the University Ethics Committee. Ten oesophageal cancer survivors were contacted via the Oesophageal Patients' Association (OPA) and asked to participate in the study. The OPA is a peer support group for individuals who have had cancer of the oesophagus, their family and friends. Five people consented to participate: three females and two males whose ages ranged from 56 years to 77 years. The length of time since diagnosis ranged from three to 17 years and all participants had undergone surgery. One participant was still in employment, three had retired either because of age or as a result of their illness, and one participant described that she worked at home, caring for her family. All the names of the participants and the people that they refer to have been changed to ensure confidentiality.

Procedure and analytic approach

Data generation and analysis were guided by the principles of Interpretative Phenomenological

Analysis (IPA) (Smith, 2004; Smith, Jarman, & Osborn, 1999). IPA is a phenomenological approach which involves a detailed examination of the person's experience and is focused on understanding the individual's personal perception of their experience and thoughts, while acknowledging that the participant's perceptions are elicited through a dynamic, interactive process, and interpreted by the researcher (who has their own beliefs and understandings). IPA is committed to an idiographic analysis of a small sample, aimed at an in-depth analysis of each case which will highlight a general story about all of the participants, as well as highlighting the uniqueness of each case (Brocki & Wearden, 2006; Larkin, Watts, & Clifton, 2006; Smith, 2004). Semi-structured interviews were conducted with participants either at the participant's home or at the affiliated university. The interview schedule was developed as a result of a review of the literature on cancer. The review identified experiences and challenges associated with cancer, which informed a list of potential discussion topics on the interview schedule: physical and social impact of oesophageal cancer since diagnosis; coping; lifestyle change; thoughts and beliefs about the illness; and fears of recurrence. However, as the interviews aimed to capture the richness and complexity of participants' experiences and meaning making, the interview was allowed to progress along a course opened up by the participant rather than being dictated by the interview schedule. The interviewer used open-ended non-directive questions with minimal probes. Interviews were subsequently transcribed, read and independently annotated by the first and second authors, and a list of first order themes elicited. A series of second order closely related themes were negotiated by the first and second authors, which aimed to cluster and reflect the meaning of the first order themes and could be influenced by other transcripts as well as knowledge of psychological theory—consistent with the inductive nature of IPA (Brocki & Wearden, 2006). The final themes presented were therefore generated from the data rather than as a result of any pre-existing formal theoretical position (Smith, 2004). Similarities and differences in the first and second order themes across participants were then noted and formed the basis for the development of a master list of themes. The transcripts were re-read in relation to this list of themes to ensure that it was comprehensive, and a list of relevant extracts was compiled for each theme. The master list of themes was then reviewed

by all authors to ensure that the process had resulted in themes which were represented in participants' transcripts, with valid and credible interpretations. Differences of opinion throughout were discussed in order to reach a consensus, and resulted in minor changes to the list of themes.

Findings

Participants' accounts were highly detailed, individualized and personally contextualized, encompassing descriptions of personal, social and medical relationships, illness and treatment experiences, eating behaviours, and spiritual and religious perspectives, but all encompassing a dimension or sense of 'change' from the pre-cancer state, and appearing to represent myriad challenges to the self-concept. Hence our findings are a summarized account of the oesophageal cancer survivor's struggle, following surgery, to readjust their identity in the face of their illness, their altered familial and societal roles and their changed relationship with food.

Eating and a sense of loss

People who have had surgery for oesophageal cancer usually experience a change to their eating habits. All of the participants interviewed indicated that they had to make adjustments to their eating patterns, and for some these changes were dramatic. Every participant indicated that eating was no longer a source of pleasure. What was once a natural and nurturing behaviour requiring little thought, was now a restricted and somewhat complicated procedure requiring planning and organization:

I have to be careful about different relishes on the food. Some things don't agree with me so I have to be careful. I cannot drink milk anymore. I can take it in tea, but I can't drink it from the bottle the way I used to ... food would stick, right here at the scar tissue, it's close to the windpipe and I would feel my breathing going and really think it's lights out. You know, you can't breathe at all because of a small thing like a pea, or even water. I get a sort of blockage, an air lock and that again causes me to be very sick, violently sick, and of course no breathing.

The first meal following surgery was perceived as an indication of treatment success, and of future eating ability. Several participants described how their first meal caused particular disappointment and distress, and described the cognitive and emotional responses to these (often failed) eating attempts:

And I was wanting food, I was hungry and I hadn't eaten for months ... you can start to eat a wee bit more [during the months after surgery], but I didn't know this and I was like, I'm never going to be able to have a normal meal again ... I did cry one day and I just thought—what can I eat?

The social aspects of eating also created challenges for participants. Relationships that were characterized by joint activities of social eating had to be renegotiated:

One of the traumatic things for me, I love cooking. I used to love eating and I would cook here in the house you know, weekends and so on, loved going out for a meal with my wife. But the most terrible thing about it is, if I look at a menu, I have to go through the embarrassment of asking for a child's portion, people look at you—is this guy mean?

This anxiety of negative appraisal by others was also reflected by other participants, who could not fully conform to socially accepted eating behaviours. For several of our participants, meal times served to reinforce the discrepancy between themselves and others:

I'm really glad when John [participant's husband] says 'Judith has trouble eating you know' cause I'm nearly willing him to please say something, so that they just don't think I'm odd, pushing this food round my plate and piling it on to his.

You feel so embarrassed, sitting and you are eating a wee corner of your meal and the waiter says 'is that all right for you, is there something wrong with that?' I say no, it's just that I'm not very hungry ... you feel people are thinking—'oh what's wrong with her, why is she not eating?'

Mathieson and Stam (1995) also describe how body failure represents a discrepancy between the healthy and the ill person, and signals to the person's social radius that he or she is a cancer patient. For our participants, eating situations were also a salient reminder for themselves of their own cancer status: 'Do you know I forget sometimes, I forget I have it ... until I go to eat.'

Relinquishing and re-negotiating roles

Many of the characteristics which form the essence of identity are linked to social roles fulfilled throughout life, and from which flow the evidence to support ideas about the self (Cheston & Bender, 1999). When these roles are restricted or eroded, then validation of

the self may also be restricted. For our participants, tensions between former roles and new identities began early. This participant describes her feelings when a colleague whom she managed and supervised at work, came to visit her in hospital:

I was lying there and I was thinking—what on earth must he think of me, lying here? Like I mean I had stitches all the way down here, my neck was swollen away out ... and I've never spoken to him about it since then and I don't think I ever probably will.

Our participants also described changes to their role within the family, and some reversal of roles was common. However, it was also important for survivors that they were allowed to re-establish their previous social and familial roles, and that their families relinquished some control as their recovery progressed. They sometimes struggled with family members to regain these positions:

So whenever the result came through it was pretty mind-blowing. But my daughter who at that stage was studying, it was a complete role reversal at that stage. She took over, she took charge and she did so until I recovered and now she says—'there's nothing wrong with you. Get on and do it yourself.' But at the time I was ill, she did everything. She just took over the running of the house. She took over everything and my care and everything, she was it.

They're beginning to realize now that I'm all right now. It took them a while ... I think she [referring to a family member] thinks I'm dying at times ... you'd have thought I was a child ... I felt like screaming sometimes and then other times I used to think I should be thankful they are there.

It is common for people to base their self-esteem on such external factors such as familial, societal and occupational roles, and this helps to explain the depth of loss experienced by participants who needed to engage in work activities in order to feel some 'worth'. Loss of work was therefore a shock for some participants, and threatened this element of their identity:

I didn't know what the hell I was going to do. What am I going to do? You know eh, it was more, I think it was more traumatic than coming out of the hospital ... it's very hard you have to take stock of all the things that are important.

I was very determined to get back to work afterwards, because I was determined that em, I wasn't going to let this beat me. This was a blip in my life that I was going to get over ... I had to

prove to myself that I was a full-time member of the human race and I was going to do my bit.

Some continuity with pre-cancer activities or responsibilities (such as social or occupational engagements) may help to preserve self-esteem and positive appraisals of the self:

They insisted that no matter what, it was my turn to do New Year's Eve [host a party] ... everybody came to my house but they all brought the food, I didn't do anything, they just came ... so that was nice.

A colleague of mine, previous colleague, asked me to do a job for him. That gave me a boost you know cause I said to myself—right, I've still some worth you know, somebody wants me.

Being unknown and being known

While we were particularly interested in the specificity of the oesophageal cancer survivor's experience, we also exposed experiences which are shared by many patients with a chronic illness, particularly cancer—where there is conflict between the reality and experience of illness for the patient, and the taxonomy of the biomedical disease. The desire to be viewed and known as an individual and not just a tumour or slab of meat (devoid of personality) was manifest for our participants particularly at the early stages of their illness experience—beginning with their experiences of the Intensive Care Unit, which were characterized by feelings of depersonalization:

All these tubes and so on dripping down me and I wasn't able to move or anything like that ... I remember at that time feeling that I was just a slab of meat ... and the nurses would come and they'd wash you and turn you and wash you and turn you.

Identity is also concerned with differentiation from others, and our participants stressed the value of personal aspects of relationships with medical staff. This human connection with medical staff and being known has been shown to be a prominent theme for other people with cancer (Thorne et al., 2005). For our participants 'being known' was represented on a very basic physiological level, but also on a more personal level, perceived by patients to be beyond the normal realms of the doctor-patient relationship:

He knows me inside out ... He would have sat with me in the afternoon, when he wasn't working, you know on his day off, or would have

come round with me at any time and just sat with me you know.

Familiarity, trust, and especially faith (for example, in their medical expertise) were defining characteristics of this reciprocal relationship:

I knew I was in good hands and I knew that Mr Smith [surgeon] had a very good reputation and I felt safe ... it's very important to have faith in the people that were dealing with you and I did have.

A shared identity

The importance of receiving information from people who demonstrated lived experience of oesophageal cancer was stressed by participants, who reported that information from peers (particularly those who had survived a number of years) would have been particularly beneficial during the early stages of their illness at the time of diagnosis and shortly following the surgery:

Now if somebody had came in and said 'look, I had this done a year ago, look at me' now that would have been all right ... I suppose they [the surgeons] don't know, they haven't been through it, they don't really know themselves. They do the operation, save your life and eh, then it's up to you.

Previous research has demonstrated that peer support groups provide shared understanding, positive role models and information regarding coping, which would not be available from friends and family (Dakof & Taylor, 1990). Indeed, while our participants described how the *presence* of their family was a key characteristic within their environment after surgery, they thought that peers (described by one participant as 'The Cancer Club') could provide normalization of feelings, reassurance, non-defensive relating, hope and inspiration:

We would talk over different fears that we would have, whereas I wouldn't talk about them with friends who hadn't gone through that situation ... I find you can talk to people like that and say ... this is natural to feel this way you know, there's nothing wrong with feeling that way. You can talk to them in a much more personal way because of your experiences.

Another participant's experience however, may illustrate the limitations of upward social comparison—that it is only beneficial if the individual believes they are likely to follow a similarly favourable path. One participant found it distressing to

listen to other people's experiences with cancer, perhaps because it reminded him of his own vulnerability: 'The only way it affects me is if I hear of someone else having it ... there's a friend of mine a friend of ours died last week ... things like that seem to affect me very much now.'

Personal growth: integration of old and new identities

Cancer can threaten the continuity in one's identity, and personal narratives are transformed to incorporate the experiences of illness. Participants often distinguished between their old pre-cancer self and their new identity, and for some, this was associated with feelings of loss:

If I don't compare what I have now and don't compare what I used to have, there's no point. If I was to do that, that would really depress me now. I don't compare the past, the past is behind that door.

There were also many reports of personal growth as a result of the cancer experience, and positive results of having coped with its challenges. Although our participants sometimes wrestled with existential issues, they also experienced a new appreciation of their existence, spirituality and a re-ordering of priorities, or a new and different quality of life. One participant found that his existing beliefs about the world were challenged and he felt differently about a previously enjoyed hobby:

I'd love to be up there with my rifle you know, shoot a few rabbits and then I said to myself—Jesus you don't want to shoot rabbits, you don't want to kill anything ... I began to appreciate things more, growing things.

Growth also involves becoming aware of previous undiscovered strengths and developing new coping skills. Frank (1995) describes this as the 'quest' narrative—where cancer may bring out new aspects of the individual, making them a better person than before.

This participant now chooses to engage in more creative activities such as painting and playing music. He describes a rebirth following his cancer diagnosis and surgery:

My future started. If somebody asks to me—what age are you? Eh, physically I'm 63, mentally I'm maybe 23, but in reality, you know, I was born in 1994 [time of cancer diagnosis and surgery]. It's like a re-birth you know, a whole new life.

Although many participants emphasized changes in their outlook, for some participants it was also

important that they re-connected with aspects of the pre-cancer self. Charmaz (1997) talks about 'identity dilemmas' posed by chronic illness, and how individuals attempt to recapture a past self in order to preserve a current self which implies 'maintaining essential qualities, attributes and identities of this past self that fundamentally shape the self concept' (Gillies & Johnston, 2004, p. 436). One participant said that many years following his surgery, he unexpectedly found himself playing guitar with a friend. He had a powerful re-connection with his old self:

Just then bang, it was like somebody hit me with a hammer ... I realized I hadn't had a guitar in my hand for almost six years ... that sort of brought me down to earth and I realized I had sort of neglected because of my new lifestyle ... so I started my art again, I started my music again.

Changes in perspectives about illness, including representations of cancer, were also evident. One participant chose not to tell her daughter that she had cancer when she was diagnosed, because her daughter 'would hear the word cancer and think—that's my mummy away'. This account may be more likely to reflect the *participant's* previously held beliefs about the severity and consequences of cancer, which through personal experience, were somewhat modified: 'Well cancer is always "The Big C" ... once you get it, that's it. But it's not like that nowadays and we have proved it's not like that these days ... we are living.'

Conclusions

The saliency of the concept of identity in representing participants' attempts to find meaning and make sense of their experiences became apparent during analysis. While identity therefore provides a framework for our emergent account, we are also conscious of the varied theoretical conceptualizations of the concept (Crossley, 2000), and recognize the impact of the interview process itself—particularly the generation of narratives, which are argued by some to be the very process of identity construction (Mathieson & Stam, 1995). Nonetheless, most conceptualizations of identity suggest that one's self-concept is socially constructed and reflects interactions with others and society—a typified self at a stage in the life course situated in the context of organized social relationships (Weigert, Teitge, & Teitge, 1986).

Illness may challenge an individual's sense of identity and forces an alteration and renegotiation of its elements (Charmaz, 1997). In general terms we know that a cancer diagnosis may result in some loss of productive functioning, altered roles, financial strain, personal distress, family stress and stigma, resulting in an assault on personal and social identity (Carpenter, Brockopp, & Andrykowski, 1999; Mathieson & Stam, 1995). However, the challenges presented by cancer to the maintenance and readjustment of a sense of self over time may be highly individualized, and there is variability in the extent to which cancer forms part of the survivor's identity—years after treatment many prostate survivors feel little need to form a significant part of their identity around their cancer experience (Bellizzi & Blank, 2007). For our oesophageal cancer survivors, maintenance and differentiation of identity was threatened by changed relationships with food, the biomedical treatment of the disease and altered familial and societal roles. Adjustments in identity involved personal growth, regaining aspects of the pre-cancer self and incorporating aspects of the illness experience.

Previous research has identified among different populations of cancer patients, similar experiences of role erosion and renegotiation (Bellizzi & Blank, 2007; Gillies & Johnston, 2004; McCorry, Dempster, Clarke, & Doyle, 2009), bodily disruption (Mathieson & Stam, 1995; Wainwright et al., 2007), personal growth (Cordova, Cunningham, Carlson, & Andrykowski, 2001; Mystakidou, Tsilika, Parpa, Galanos, & Vlahos, 2008), unique characteristics of peer support (Edelman, Craig, & Kidman, 2000; Fawzy, Fawzy, Arndt, & Pasnau, 1995; McCorry et al., 2009) and biographical work, such as that described in detail by Mathieson and Stam (1995). Our interview data have contextualized these experiences among oesophageal cancer survivors, and have also highlighted the significant physical, social and emotional impact of changed eating abilities post-surgery which are more uniquely salient within this patient group. In particular, the mismatch of unrealistic expectations and patient experience of post-surgery eating, the potential for disrupted relationships and social activities and the challenges of restoring stability in relation to eating can be psychologically difficult for survivors. Eating situations are the most obvious reminder (to the self and others) of the individual's cancer status. Wainwright et al. (2007) argue that learning to eat after surgery can be just as difficult

as learning to walk again following amputation of a lower limb, and suggest that rehabilitation should focus on the psychosocial aspects of recovery in addition to managing physical symptoms, and should begin prior to surgery. Surviving patients (with their unique insight and credibility) could have a valuable role alongside medical professionals in preparing patients for the consequences of surgery, and in assisting oesophageal cancer patients to learn new ways to cope with food—physically, emotionally and socially. Surviving patients may also have a valuable role in assisting others with the same illness to incorporate aspects of the illness into their identity, and in emphasizing the importance of re-negotiating social and familial roles and reconnecting with the old 'pre-cancer' self as a means of achieving agency and continuity of identity. Contact with peers might also facilitate positive changes in illness and treatment beliefs, influencing decisions about treatment and improving well-being. Peer comparison has many reported advantages (Wood & VanderZee, 1997), such as the normalization of the patient's experience, the provision of opportunities for upward social comparison (Taylor & Lobel, 1989) and the creation of hope. It is possible that peer support programmes could be particularly beneficial for groups of cancer patients where there is generally less support available (Hoey, Ieropoli, White, & Jefford, 2008), such as oesophageal cancer.

A more formalized peer support initiative within the care pathway may be most effective if it addressed patient (and carer) expectations about recovery and adaptation *prior* to surgery (Deardoff, 2000), including patient and carer illness and treatment representations and the meanings associated with eating experiences, since these are imperative to coping, well-being and various illness outcomes (Bowen et al., 2003; Leventhal, Meyer, & Nerenz, 1980; Orbell, Hagger, Brown, & Tidy, 2006; Rabin & Pinto, 2006).

Our participants were generally positive about the medical professionals involved in their care, and this satisfaction appeared largely to be a result of the individualized characteristics of their relationships with medical personnel. As such, medical professionals, by accommodating notions of patient identity and reducing objectification of the individual, can provide care which nurtures and maintains the patient's sense of self, therefore providing opportunities for growth and contributing positively to the patient's passage through the disease trajectory.

Methodological reflections and future directions

We have reported a fine-grained analysis of the experiences of a small sample of survivors of oesophageal cancer, consistent with our goals and those of IPA, where a consensus towards the use of smaller sample sizes (and greater sensitivity to subtle inflections of meaning) seems to be emerging (Brocki & Wearden, 2006; Smith, 2004). While we have attempted to preserve the individual account, the very act of summarizing infringes somewhat upon the uniqueness of each participant's narrative. We are also mindful of the place of the researcher and interviewer who presents themselves as a health professional rather than a peer, and is therefore privy to different articulations than for example, a peer or family member (Richards & Emslie, 2000).

We have not sought the experiences of the population of oesophageal cancer patients who are unsuitable for surgery, and these patients are difficult to access. Nor have we addressed the experience of patients more immediately post-surgery or pre-surgery, and the retrospective accounts provided by our longer term survivors may not be a good representation of the salient challenges associated with this period. However, our participants' retrospective accounts of their own experiences following surgery indicated that this was a difficult period of transition, when failed eating attempts caused significant distress, and threats to identity were felt most sharply.

In addition, all our participants (as members of a patient support organization) are likely to be proponents of peer support. However, peer support may not be acceptable to all (or even the majority of) patients. Mills and Sullilvan (2000) were positive about other patients as a source of information, but also noted the need for care in the implementation of peer advice, as not all encounters with other patients were beneficial. Future research might investigate more directly the potential content, mode and timing of a peer intervention among oesophageal cancer patients. In addition, patients attending support groups are likely to be more highly educated, to desire more information and to use more adaptive coping (Grande, Myers, & Sutton, 2006). Future enquiry might usefully be directed at research samples with different patient characteristics.

Identity provides a useful framework for helping to understand the processes of physical, social and emotional adjustment following surgery for oesophageal

cancer. By exploring the personal accounts of our participants we hope that clinicians and researchers might better understand the breadth of challenges negotiated by survivors of oesophageal cancer, and hence tailor their advice, support and intervention to best meet the needs of the individual. It is imperative that patients renegotiate their identity with family, friends, co-workers and medical personnel. The importance of attempts to nurture and maintain a sense of self, and the implications for adjustment and well-being should be recognized by those providing care.

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Author biographies

CEARA CLARKE, DCLinPsych, is a clinical psychologist with the Child and Adolescent Mental Health Service, Northern Health & Social Care Trust, Northern Ireland, UK.

NOLEEN K. MCCORRY, PhD, is a health psychologist and lecturer at the Queen's University of Belfast and South Eastern Health and Social Care Trust in Belfast, Northern Ireland, UK.

MARTIN DEMPSTER, PhD, is a health psychologist and research co-ordinator for the Doctorate in Clinical Psychology Programme at the Queen's University of Belfast, Northern Ireland, UK. His research interests focus on the psychological wellbeing of people with chronic illness.