

# A new normal: reconciling change in appearance and function for men with head and neck cancer

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None declared

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## Abstract

**Aim** The aim of this study was to explore how men with head and neck cancer (HNC) experience appearance and functional change following diagnosis.

**Method** Grounded theory methodology was chosen and 12 retrospective semi-structured interviews were undertaken with men who were 12 to 24 months post-diagnosis.

**Findings** Three interrelated categories emerged from the data: normalising change, 'being under siege'; getting through treatment and reclaiming self. The core category was reconciling change: a new normal that reflects the social and psychological processes involved in accommodating and assimilating change in appearance and function for men with HNC.

**Conclusion** The substantive theory provides insight into how men with HNC prioritise function and actively distance themselves from concerns about appearance. Furthermore, it identifies that men may be at risk of social anxiety and isolation where there are multiple changes or body incompetence and these findings should inform clinical practice and care provision.

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## Keywords

body image, cancer, head and neck cancer, patients, patient experience, quality of life

## Introduction

Head and neck cancer (HNC) describes cancers that arise from the surface mucosa of the upper aerodigestive tract and the main tumour subsites are the oropharynx, oral cavity and larynx (National Institute for Health and Care Excellence (NICE) 2004). There is a disproportionately large number of patients diagnosed with HNC every year in Scotland, HNC is the sixth most common cancer in Scotland accounting for 3.9% of all cancers, and nearly half of all patients diagnosed with HNC are from the West of Scotland ( $n=596$ ) (West of Scotland Cancer Network (WoSCAN) 2013). There is also a marked gender difference with HNC occurring more often in men, and it is the fourth most common cancer with 408 cases per year (WoSCAN 2013). By comparison, it is the eighth most common cancer in women with approximately 188 cases per year (WoSCAN 2013).

Tobacco and alcohol are the major risk

factors for HNC (NICE 2004, Scottish Intercollegiate Guideline Network (SIGN) 2006), which primarily occurs in the over 60 age group and the most disadvantaged socio-economic groups. However, human papilloma virus-related oropharyngeal cancer is increasing in younger, more affluent people without other risk factors (Mehanna et al 2013). In HNC, 60% of patients present with advanced stage disease, which affects treatment options and mortality (WoSCAN 2013). While many patients complete their primary treatment and return to previous levels of health and well-being, a significant proportion experience a range of distressing physical, social, financial and emotional long-term problems (Macmillan Cancer Support 2013, National Cancer Survivorship Initiative 2013).

## Background

Patients who present early with localised disease can be treated with either surgery or

## Implications for practice

- This substantive theory emphasises the process of reconciling change and identifies men's focus following diagnosis of head and neck cancer and treatment. It also highlights men who may be at risk of social anxiety and isolation
- The period following treatment is important in terms of supporting accommodation and assimilation of change. Information from healthcare professionals and cancer patients is essential for rehabilitation and development of a 'new normal'
- Participants were shocked by their cancer diagnosis and prioritised survival with little consideration of the potential short- and long-term changes in their appearance and function. Clinicians should consider this finding particularly in relation to communication, information provision and informed consent
- The participants attempted to maintain independence and control, and frequently presented themselves as unchanged. Therefore, support should be provided proactively during and after treatment as men do not generally disclose their needs or initiate support
- Holistic needs assessments are central to the provision of support and where possible should be undertaken at important time points around diagnosis, at the end of treatment and three months after treatment to develop care plans

radiotherapy, while combined treatment is usually necessary for advanced disease (SIGN 2006). Although multimodality treatment improves outcomes, it can have a significant effect on appearance and function. Patients with HNC have been found to have fewer appearance-related concerns than those with non cancer-related disfigurement (Newell 1999, Katz et al 2003, Furness et al 2006). Katre et al (2008) suggested that the characteristics of patients with HNC may mean that self-image is less important before treatment, while other research suggests that this patient group regards appearance change as the price to pay for survival (Larsson et al 2007, Semple et al 2008).

However, younger patients, under 55 years of age, have been found to display significantly higher levels of dissatisfaction with their appearance (Katz et al 2003, Katre et al 2008, Fingeret et al 2012). Difficulties relate to social encounters, particularly with strangers, when people experience feelings of anxiety and embarrassment.

The most striking conclusion from the literature is that there is no demonstrable relationship between size, severity and visibility of appearance change and psychological distress (White 2000, Thompson and Kent 2001, Katz et al 2003). Patients may not express their concerns about appearance and often these issues are not addressed because of other treatment priorities (Millsopp et al 2006, Konradsen et al 2009).

Despite improvements in treatment, taste and vocal changes, oral pain, dryness and narrowness result in losses on different levels in daily life (Larsson et al 2003, 2007, Roing et al 2007). The effect of cancer treatment is frequently unexpected and as signs and symptoms increase normal function becomes difficult, and habits that were once pleasurable and routines that were taken for granted acquire new meanings (Larsson et al 2003, Roing et al 2007, McQuestion et al 2011). Eating in particular is affected, therefore mealtimes are no longer social and enjoyable occasions (Larsson et al 2003, 2007, Roing et al 2007).

### Aim

Qualitative HNC research has focused on specific cancers, treatments, time points or issues. Furthermore, HNC is more prevalent in men and people frequently require multimodality treatment. Therefore, a robust study of how men with HNC experience appearance and functional change in the first 12 months following diagnosis was required, and led to the following research questions:

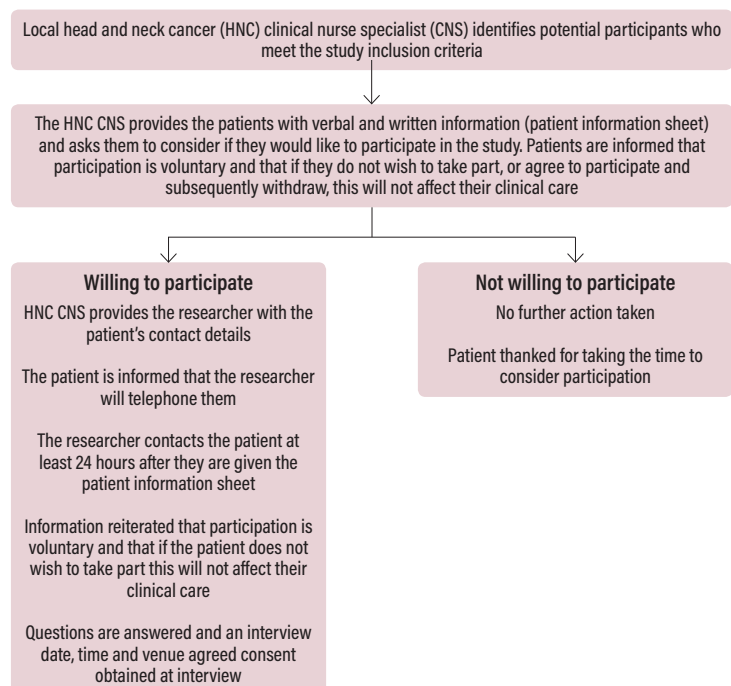
- » What appearance and functional issues are important for men diagnosed with HNC?
- » How are appearance and functional issues experienced in the context of a life-threatening diagnosis of HNC?
- » At what point in the care pathway are appearance and functional issues important?

### Method

Qualitative research was the most appropriate approach as there was limited knowledge

**TABLE 1. Participant information**

| Participant | Age | Staging  | Treatment   |
|-------------|-----|--|---|
| 1           | 63  | T1N2aM0 left oropharynx                        | Left neck dissection<br>Postoperative chemo-radiotherapy              |
| 2           | 58  | T4N1M0 left oropharynx                         | Major surgery with reconstruction<br>Postoperative chemo-radiotherapy |
| 3           | 63  | T4bN2bM0 oropharynx                            | Chemotherapy<br>Chemoradiotherapy                                     |
| 4           | 55  | T4N2cM0 larynx                                 | Laryngectomy<br>Chemoradiotherapy                                     |
| 5           | 61  | T1N2aM0 left oropharynx/T1N1 right oral cavity | Chemoradiotherapy   |
| 6           | 68  | T2N2aM0 left base of tongue                    | Chemoradiotherapy   |
| 7           | 65  | T2N0M0 oral cavity                             | Major surgery with reconstruction<br>Postoperative radiotherapy       |
| 8           | 58  | T2N0M0 tongue                                  | Major surgery with reconstruction                                     |
| 9           | 57  | T2N1M0 tongue                                  | Major surgery with reconstruction<br>Postoperative chemoradiotherapy  |
| 10          | 26  | Mucoepidermoid cancer hard palate              | Wide local excision with obturator<br>Delayed reconstruction          |
| 11          | 56  | T4N2bM0 larynx                                 | Laryngectomy and right neck dissection<br>Postoperative radiotherapy  |
| 12          | 64  | T2N0M0 right oral cavity                       | Major surgery with reconstruction                                     |

**Figure 1. Flow chart illustrating participant recruitment**

on the topic and this method focuses on the way people interpret and make sense of their experiences and the world in which they live. Qualitative research places researchers in the world of those being studied to make this world visible and understandable to others. When deciding on a qualitative approach the researcher considered phenomenology and grounded theory as they are the two main methods used in nursing research. Grounded theory was chosen as it attempts to go beyond description and build theory about social and psychological phenomena (Glaser and Strauss 1967, Corbin and Strauss 2008, 2015). Strauss and Corbin's (2008, 2015) approach to grounded theory was followed because it provides guidelines and procedures.

### Participants

The study population was men with a diagnosis of HNC from two acute hospital sites in the West of Scotland and who were a minimum of 12 and a maximum of 24 months post-diagnosis. This time period following diagnosis was chosen as quality of life data suggest that results at 12 months are indicative of longer term outcomes (Millsopp et al 2006). Random sampling was used initially, then following analysis data were collected from specific participants to develop concepts and relationships between concepts (Corbin and Strauss 2008, Charmaz 2011). Overall, the participants were representative of men with HNC in the West of Scotland with reference to age, stage of disease, treatment, deprivation, education level and employment. Participant information is given in Table 1.

### Data collection

The process of participant recruitment is described in the flow chart in Figure 1.

Twelve retrospective semi-structured interviews were undertaken as interviews can allow exploration of hidden and suppressed views (Charmaz 2006). A sample size of 12 is satisfactory when exploring peoples' experiences in a relatively homogenous sample (Guest et al 2006). A discussion guide was developed, in collaboration with two men with HNC, consisting of introductory comments, open questions for discussion and closing questions. Ethical approval was obtained from the University of Stirling Health Studies Research Ethics Committee, the West of Scotland Research Ethics Committee and NHS Research and Development department.

As advised by lay members of the ethics committee, participants were informed of the researcher's background as an HNC clinical

nurse specialist (CNS) to reduce potential anxiety about communication. Interviews were performed in participants' homes ( $n=11$ ) or an NHS facility ( $n=1$ ) over 12 months (January to December 2012) and lasted between 45 and 60 minutes. Participants were given the opportunity to ask questions before consent was obtained on the day of the interview, and were reminded that they could withdraw from the study or stop the interview at any time, and that this would not affect their ongoing care. The patients' consultants, GPs and CNSs were advised of interview participation in case support was required.

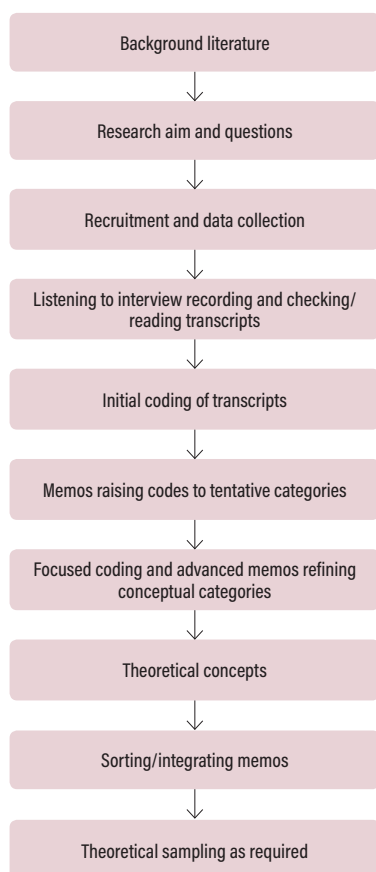
## Findings

An overview of the grounded theory process is given in Figure 2. Participants were given a unique identifier, interviews were transcribed verbatim and data were anonymised and stored following University of Stirling guidelines. Data were collected between January and December 2012 and analysis began following the initial interview, and proceeded throughout and following completion of the interviews.

This allowed comparison of data within and between interviews, and memos were written to identify codes and categories. This constant comparison identified variation and defined relationships between categories. Memos became more detailed and refined as analysis raised initial codes to tentative categories. Questions were asked based on analysis during subsequent interviews and two participants were recruited to develop construction of theory. Interviews and analyses were performed by the researcher, while two university supervisors reviewed a sample of the analysis and doctoral assessors reviewed, challenged and supported development of the emergent categories and substantive theory.

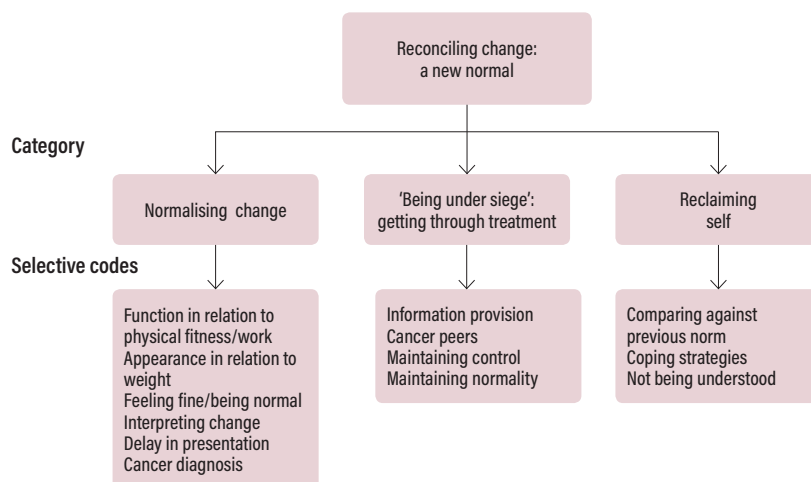
Figure 3 summarises the findings and analytic process from coding to categorisation and identification of the core category, while Figure 4 highlights the substantive theory of the experience of appearance and functional change for men with head and neck cancer in the first 12 months following diagnosis. Findings are presented in relation to each category and participants' quotes are used

**Figure 2.** The grounded theory process

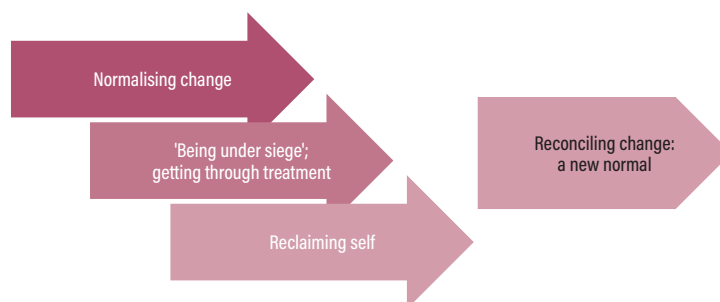


**Figure 3.** Findings and coding/categorisation process

### Core category



**Figure 4.** Substantive theory of the experience of appearance and functional change for men with head and neck cancer in the first 12 months following diagnosis



to illustrate the process of analysis and categorisation. The quotes highlight properties and dimensions of categories, and reflect similarities and differences in participants' perceptions and experiences. Finally, the relationship between the categories is described and the core category is explained.

### Normalising change

The participants struggled to articulate what they thought or felt about their bodies before their HNC diagnosis and gave them little consideration as long as they could maintain function and perform social roles. They frequently normalised change by interpreting it as 'normal' or 'minor', which resulted in delays in presentation, and they generally presented to healthcare professionals because of changes in function rather than appearance:

*'I had a pain in my throat you see. I had been bothered with sore throats all my life, which is probably why the cancer got to the stage before I went and did something about it. I was getting a sore throat and assuming it was the old problems so I would say I would go to the doctor but within a couple of days it would go away so I didnae (did not) bother myself, I think that went on for maybe a year or more'* (participant (P) 6).

Another participant said:

*'I went to the doctor because I was getting a sore hip. My hip was bothering me running on the road. It was no bad on the soft ground but on the road. So I actually went to the doctor and it was Dr X and I was sitting talking to him about my hip and he kept looking at me and it was the way he was looking at me. He said "have you got some swelling on you?" I said I think it must be my glands and he came round and actually had a feel at my neck. "I think we should be having a little look at this before we can do anything with your hip. It could just be swollen glands but it is more important at this time just to get this checked out"'* (P5).

Family and friends legitimised the importance of the change by reassuring the men that it was not normal and that they should present to a healthcare professional. Overall, there was a lack of awareness of HNC signs and symptoms. A diagnosis of cancer immediately raised issues of a changed and uncertain future that affected the participants' experiences of changes in appearance and function.

### 'Being under siege': getting through treatment

Following an HNC diagnosis the participants' focused on surviving cancer and getting

through treatment, regardless of the changes they experienced, and information about treatment and change in appearance and function was difficult to process at this point. The information modified the changes the men experienced by increasing their knowledge and allowing them to try to manage the changes and maintain control, however it could not fully prepare them for their experience of changes, particularly when they were severe or unusual. Changes that influenced basic functions such as breathing or speaking were challenging even when experienced for a short period, as they increased feelings of vulnerability and reduced independence:

*'You feel like you are just living in a body and you have no control over it, you cannae (cannot) do nothing about it. You can make signs, but it is still like you are not in control, put it that way'* (P2).

Scarring was generally considered to be unnoticeable to others therefore the men could maintain normality and present themselves as unchanged. The participants used avoidance or camouflage occasionally but only during the immediate post-operative period. Men actively distanced themselves from concern about appearance and issues such as hair loss were discussed in functional terms:

*'I did wear a hat when I was out and about. That wasnae (was not) vanity, it was sensibility because I had nothing to protect my head so I wore my hat then. Other than that it didnae bother me'* (P3).

Radiotherapy or concurrent chemoradiotherapy caused changes to saliva, taste, swallowing and speech, and the main result was marked weight and muscle loss. During treatment the participants accepted these changes as they compared themselves to other cancer patients who were worse off. When their physical condition changed, and they became 'the person with the nasogastric feeding tube' or required support with general activities, the participants rationalised this through cognitive reappraisal where they focused on the need for and benefits of treatment:

*'I remember as well, after I had had the last dose of chemotherapy, I was still on radiotherapy and instead of making my own way down to the radiotherapy suite I had to be wheeled. I did not have the energy to walk even down the corridor or the ward'* (P1). The researcher asked P1 how this made him feel, to which he responded:

*'I was not too fussed about it in a lot of ways. I felt okay. I know what is going on here. I know this stuff is toxic and that it is affecting*

*my system. I have got to go with the flow. I have got to finish the radiotherapy. I cannot not do it and it is the combination of the radiotherapy and the chemotherapy that is going to attack the cancer cells. I am just going to have to put up with it'* (P1).

A main component of coping with appearance and functional change and getting through treatment involved the men trying to limit intrusion into their daily lives by following advice from healthcare professionals, minimising reliance on others and maintaining control. Other cancer patients provided meaningful information and allowed the men to view their experience as normal. There was a sense of camaraderie and shared understanding between patients and this provided the men with a sense of belonging during a period when they felt detached from their usual life. However, much of the focus on information sharing was related to the practical management of changes with little emotional disclosure. Following treatment the men's experiences of change in appearance and function was interpreted differently.

### Reclaiming self

During treatment the participants were mainly exposed to other cancer patients experiencing similar changes and therefore felt a level of acceptance. At this time these other patients formed the participants' points of reference for comparison rather than their healthy peers:

*'Aye knowing that you are in a room with one another. That is the size of it basically – you are accepted there'* (P2).

While social isolation is not inevitable the participants had to make a conscious effort to socialise during treatment. Social isolation frequently occurred as treatment progressed due to the side-effects and the time taken to attend treatment and perform self-care, which meant that the men were mainly in contact with patients, healthcare professionals and family in a safe environment.

After completion of treatment the participants started to compare themselves with how their bodies used to look and function and began to reclaim important aspects of self. While they initially distanced themselves from concerns about appearance, they became concerned about weight and muscle loss because of its associated effects on physical function and maintenance of social roles.

The importance of eating was evident, but the challenge of finding suitable things to eat could not be underestimated. This process of 'not knowing' what they could eat, what to do for the best, if things would improve or

when they would improve was difficult and frustrating. The men talked about having 'good' and 'bad' days and variation throughout the day, particularly during the initial post-treatment period:

*'The bad days are not as often nor as they were but as I say, it is just a case of keeping myself aware of it'* (change to speech). *You cannot know what is going to happen in the space of a day. You can be speaking fine at one point in the morning and in the afternoon you can find that you start to babble again... People basically tend to be more impressed than I am (about the speech)'* (P8).

The combination of multiple changes to appearance and function could result in loss of self-confidence and self-esteem, and this was particularly evident for those men who had a laryngectomy or experienced oral incompetence and nasal regurgitation. Lack of control of speech or bodily fluids, such as saliva and sputum, caused embarrassment and fear that could result in social anxiety and isolation. Men who had a laryngectomy experienced social stigma and felt that others did not understand the changes they experienced, which increased their vulnerability.

The participants became more aware of variability and nuances that were specific to them and modified their behaviours and refined techniques to try to accommodate the changes and improve function over time. CNSs played an important role in discussing techniques to manage appearance and functional changes, both physically and psychologically during social interaction. Family members were also integral to the process of social re-integration. Men used different methods of coping at different times and in different situations, including trial and error, planning ahead and graded exposure:

*'I think I would feel embarrassed sitting in a restaurant. I mean my cancer nurse specialist and my wife say: "Well sit with your back to people, you know, and they will no (not) see you." I am scared of this running down my chin and liquids coming down my nose, things like that. It is embarrassing you know'* (P7).

*'The only problem I have is eating because I cannot feel that so obviously when I am eating if there is anything that runs then I do not know. So actually I have got a small mirror which I use when I am eating to see when eating in the house. When we are out, the wife tells me if there is anything at the corner of my mouth'* (P12).

*'I tried to prepare for different things happening when I started to go out. At first I tried to avoid people and sometimes other*

*people tried to avoid me. I took my note pad and pen everywhere at first and had written lots of things out in case I needed it' (P10).*

Having considered the major categories normalising change, 'being under siege'; getting through treatment and reclaiming self, the core category reconciling change: a new normal is presented below.

#### **Reconciling change: a new normal**

This core category describes the basic psychosocial process of accommodating and assimilating change in appearance and function for men with HNC. Normalising change, 'being under siege'; getting through treatment and reclaiming self, interact with and inform one another leading to reconciling change: a new normal. Men with HNC experience numerous and significant changes in function that they attempt to incorporate into their lives. There is a sense of freedom being affected when everyday tasks, particularly speaking and eating, must be considered consciously to varying degrees. Participants learned to live with the changes in function by acknowledging loss and accommodating their limitations. Central to this process was getting back important aspects of their lives and regaining control:

*'I am getting myself back. I am in control. But you have got to see yourself moving forward if you know what I mean' (P12).*

While participants reclaimed aspects of their former lives and selves often they started to realise that they were changed forever by the experience of the cancer diagnosis and changes in function and/or appearance. As time went on participants had to consider changes in function consciously less often and developed a 'new normal'. This was assimilated into their daily lives by themselves and by others who knew them, as the following quotations suggest:

*'I cannot open my mouth the same as I used to. So when I use the fork with the prongs down the food would hit my top lip and fall back down onto my plate. It got a bit frustrating, but you just turn the fork round the other way. It is just things like that basically' (P12).*

*'They all know me, so I think they all sort of accept the fact that when I speak my speech is not always that clear. Nobody is going to turn round and say "you speak kinda funny son" you know, but people have learned to sort of expect that' (P8).*

For most participants feeling diminished was temporary, however for some their life and future was diminished. Further

medical intervention was considered for issues of concern that participants felt were critical to function:

*'I hope things change as I do not want to live the rest of my life like this. I have lowered the bar so to speak though. I hoped that surgery would allow me to straighten my head and allow me to speak without using an electrolarynx, but now I would settle for one or the other' (P11).*

While dental rehabilitation was important to the men, they struggled with the thought of further surgery for cosmetic purposes.

For a few of the participants who worked at the time of diagnosis the changes in function led to a change in their duties or early retirement, which could be difficult to cope with when it was not planned. The importance of work in maintaining self-identity was evident and the men generally felt diminished when they were unable to work. For those who kept working or returned to work a few months after treatment continuing with 'normal life' allowed them to distance themselves from illness and marginalise the effect of the changes in function in terms of their lives.

There is limited disclosure about cancer and cancer experiences between men, which reduces opportunities for support, and despite increasing recognition that people live with and beyond cancer it is still associated with dying. Men may feel more comfortable talking about their cancer and treatment in retrospect, allowing them to reframe their experiences as a story of achievement. This also permits them to distance themselves from the emotions they might have felt during the cancer experience itself. During the interviews the participants talked about the importance of positive thinking and finding benefits from their experience. Positive thinking allowed them to adapt to change and see their future as enhanced. In general, having cancer made the participants reconsider their priorities. While the effects of a cancer diagnosis cannot be underestimated, there comes a point, generally between 12 and 18 months after diagnosis, where the participants assimilated changes to their appearance and function, and defined themselves as 'fine' and 'good' again:

*'I do not see myself as being a cancer patient any more. As far as I am concerned, I had it, they got rid of it, goodbye. That is it' (P8).*

#### **Discussion**

This is the first study to focus on the experiences of men with HNC in relation to appearance and functional changes over

time. A cancer diagnosis has a profound and direct effect on the reconciliation of change, particularly at the point of diagnosis, during treatment and in the acute recovery phase when survival is the focus. The emerging theory identified that before their diagnosis the men prioritised function and performance of social roles and normalised the changes they experienced, which frequently led to delays in presentation. The participants often compared themselves to others who they considered worse off or who might find change more difficult, for example younger or single men. While weight and muscle loss were accepted during treatment, as these were associated with the effects of treatment, thereafter appearance became an indicator of recovery and cultural norms became more important as the men started to interact socially again. A muscular body communicates strength, competence, confidence, power and independence (Petrie and Greenleaf 2012).

Following an HNC diagnosis the men experienced disruption to many aspects of their lives, including eating, speaking, relationships, socialising, working and self-identity. They frequently tried to normalise the changes and carry on with daily routines to maintain control and their sense of identity. When they were unable to do this they viewed the changes through an acute lens and focused on getting through treatment while waiting on recovery. During and after treatment the men's daily lives and routines were dominated by self-care and they frequently felt distanced and disengaged from normal life. The participants experienced variation in function throughout the day and from day to day, and uncertainty about recovery.

Men who experienced multiple, extreme or unexpected changes found it more difficult to accommodate, assimilate and reconcile the changes. Short-term social avoidance was useful, but ongoing avoidance signified difficulty adapting to the changes. This supports Newell's (1999) fear avoidance model of social anxiety among people with a visible difference, which proposes a continuum of confrontational and avoidant responses, with confrontation presumed to be more adaptive. Avoidance is prompted by fear and anticipation of negative outcomes, for example intrusions such as staring, comments and questions, and leads individuals to engage in a reducing range of activities as more situations are determined as threatening. Fear and avoidance are therefore conceptualised as potential mediators for adjustment and distress. The men who were unable to control their secretions and speech were at higher risk

of avoidance and social isolation.

Charmaz (1983) noted that the greater the loss of control and the amount of potential embarrassment from the illness, the more likely it is that an individual's self-concept will be affected. After treatment the participants waited initially on recovery and tried to reclaim important aspects of self and social roles, and returning to work was central to this process. Brennan (2001) suggested that the burden of many months of treatment often reduces opportunities for people to engage in work and other social roles that formerly provided feedback about their competence and value in the world. Work signifies normality and forms a central basis for self-identity and self-esteem, provides financial security, forms and maintains social relationships and represents individuals' abilities, talents and health (Wells et al 2013). Charmaz (1983) stated that in a society that emphasises doing, not being, those who cannot perform conventional tasks and social obligations lose the very means needed to sustain a meaningful life. Maintaining a normal life or returning to one therefore becomes the symbol of a valued self (Charmaz 1983, Bury 1991).

Only two participants experienced ongoing loss and a diminished self where they experienced a pervasive change across all domains of life. Restrictions can result in an all-consuming retreat into illness as the illness structures individuals' worlds and self-concepts (Charmaz 1983). Most of the participants reconciled change and developed a new normal. The concept of a new normal is identified in patients and care givers in other studies of food, eating and meals following radiotherapy for HNC (Penner et al 2012, Ottosson et al 2013). In a study of patients with breast, lung and prostate cancer Baker et al (2014) reported that people talked about getting back to normal, but presented two distinct accounts of normality. Some, particularly those who were newly diagnosed, maintained continuity to past identity by upholding previous routines, emphasising resilience and minimising the effect of cancer. Others spoke of a new normality discontinuous with their past. Most accounts, however, evidenced elements of continuity and discontinuity often in a contradictory way. This was regarded as an intermediate stage of adjustment for some patients as they later developed a sense of being a new person, changed by cancer (Baker et al 2014).

### Strengths and limitations

To ensure quality, and support discussion about analysis and theoretical development, the transcripts, memos and field notes were available to doctoral supervisors. Strategic action was taken through prolonged engagement with the data, negative case analysis, extensive description and peer review during the course of the research to increase validity and reliability (Corbin and Strauss 2008). A summary of the findings and the theoretical model that emerged was sent to two HNC CNSs and men who participated in the development of the study and the study itself, and feedback supported the model developed.

P5 said: *'Your report in many respects is very incisive and as I read and re-read it I found myself reaching for my pen to circle a remark here and a comment there and generally mentally applauding how precise your report was!'* While the small sample may be criticised, research supports that a sample size of 12 is satisfactory

when exploring individuals' experiences in a relatively homogenous sample (Kuzel 1992, Guest et al 2006).

### Conclusion

Three interrelated categories emerged from the data: normalising change, 'being under siege'; getting through treatment and reclaiming self. The core category was reconciling change: a new normal that reflects the social and psychological processes involved in accommodating and assimilating change in appearance and function for men with HNC. The substantive theory provides insight into how men with HNC prioritise function and actively distance themselves from concerns about appearance. Furthermore, it identifies that men may be at risk of social anxiety and isolation where there are multiple changes or body incompetence. These findings provide health and social care practitioners with new insights into the experience of change in appearance and function in men with HNC to inform their clinical practice.

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