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**How patients adjust psychologically to the experience of head and neck
cancer: A Grounded Theory**

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Doctorate in Clinical Psychology

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Thesis Abstract

Introduction: Head and neck cancer presents unique challenges to patients due to its effects on vital human functions and its potential for facial disfigurement. Literature discussing the associated psychosocial difficulties is growing. However, there is currently limited understanding about how patients may adjust to the physical, functional, and psychological effects experienced as a result of head and neck cancer and its treatment. Existing adjustment theories have not been grounded in patient data and often minimise the roles of emotions and other people.

Objectives: The study aimed to explore how patients with head and neck cancer adjust psychologically to their experiences, and the specific processes involved in this adjustment. The study also aimed to generate a theoretical model, grounded in patient data, to serve as a framework for informing psychological intervention.

Method: Twelve participants with diagnoses of head and neck cancer (past or present) engaged in a semi-structured interview, conducted individually. Data were transcribed verbatim and analysed using grounded theory, undertaken from a critical realist epistemology.

Results: Participants described adjustment as an ongoing, fluctuating, all-encompassing process which spanned years following cancer treatment. The core process involved participants modifying their relationship with the changes brought about by cancer, from battling against them to learning to live alongside them. Encompassed within this core process were eleven further processes which included “survive mode”, “instrumental support from others”, “making a choice”, “developing own understanding”, “acceptance”, “talking with others”, “making changes”, “redefining or regaining normality”, “barriers to progress”, “managing emotions and distressing thoughts”, and “putting things into perspective”.

Discussion: Some problems encountered by head and neck cancer patients may be unique, however, the processes participants engaged in to adjust may be similar across other cancer types and chronic illness. These processes were linked to existing theories and literature. Clinical implications include the consideration of the global impact of head and neck cancer, since all aspects of life must be adjusted. Therefore future psychological interventions must recognise this and consider patients holistically and

not focus purely on direct effects of cancer. There are also a number of research implications which include the need for additional exploration into information needs of head and neck cancer patients, exploration of the change processes associated with ‘acceptance’, the need for family and carer support, and use of longitudinal designs to track changes in adjustment over time.

Statement of Contribution

I, Louise Kate Calver, declare that this research is the product of my own original work conducted as part of the Trent Doctorate in Clinical Psychology. The project was designed in consultation with my research supervisors Dr Anna Tickle and Dr Nima Moghaddam, and field supervisor Dr Sanchia Biswas. I was fully responsible for reviewing the pertinent literature, seeking ethical approval, collecting and analysing the data, and the final write up with supervision from Dr Anna Tickle, Dr Nima Moghaddam, and Dr Sanchia Biswas. Dr Sanchia Biswas supported and assisted in the recruitment of participants for this study. A professional typist transcribed all interview data.

JOURNAL PAPER¹

¹ Written in preparation for submission to the European Journal of Cancer Care and adheres to their submission guidelines, please see Appendix 1.

How Patients Adjust Psychologically to the Experience of Head and Neck Cancer: A Grounded Theory

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Abstract

Numerous physical and psychological challenges are recognised as consequences of head and neck cancer and its treatment, but little is known about how patients adjust psychologically to these experiences. This study aimed to develop a theoretical understanding of the processes patients engage in when adjusting to head and neck cancer. Twelve patients participated in semi-structured interviews which were conducted individually and transcribed verbatim. Data were analysed using Grounded Theory methodology. Analysis generated a core category of “modifying my relationship to the changes cancer brings”, which encompassed 11 processes patients engaged in throughout their adjustment: “survive mode”, “instrumental support from others”, “making a choice”, “developing own understanding”, “acceptance”, “talking with others”, “making changes”, “redefining or regaining normality”, “managing emotions/distressing thoughts”, “putting things into perspective”, and “barriers to progress”. Contrasting findings are discussed and a model of psychological adjustment to head and neck cancer is proposed. The study found that patients engage in a series of processes throughout their adjustment to head and neck cancer, which broadly map on to the cancer treatment trajectory, though these processes did not appear to be specific to head and neck cancer. The proposed model may be used as a framework to guide psychological interventions.

Keywords: *head and neck cancer, psychological adjustment, grounded theory*

Introduction

Head and neck cancer can be devastating due to its physical and psychological effects (Larsson, Hedelin, & Athlin, 2007). In 2016, there were an estimated 930,000 cases worldwide, making it the sixth most common cancer type (Global Burden of Disease Cancer Collaboration, Fitzmaurice & Allen, 2017). A diagnosis is often quickly followed by aggressive and intrusive treatment, which may include surgery, radiotherapy, chemotherapy, or a combination thereof (Argiris, Karamouzis, Raben, & Ferris, 2008; Nigro, Denaro, Merlotti, & Merlano, 2017). Treatment effects are wide ranging and create considerable difficulties with many fundamental functions, such as breathing, eating, speaking, and swallowing, in addition to facial disfigurement, residual pain, loss of taste and smell, swelling, and excessive dry mouth (Ganzer et al., 2013; List & Bilir, 2004; Macmillan, 2015)², making it potentially the most “traumatic” cancer (Björklund, Sarvimäki, & Berg, 2010). This has led to an increased interest in the psychosocial challenges faced by head and neck cancer patients, e.g. anxiety, stress, depression, feelings of hopelessness, body image concerns, recurrence fears, and relationship problems (Fingeret et al., 2012; Shiraz, Rahtz, Bhui, Hutchinson, & Korszun, 2014; Smith, Shuman & Riba, 2017; Zabora, Brintzenhofesoc, Curbow, Hooker, & Piantadosi, 2001)³.

Defining adjustment

The term ‘adjustment’ within cancer literature is frequently used to refer to the absence, or relative absence, of psychological distress following cancer diagnosis or treatment. As such, it is often seen as the end-point of coping, rather than as the psychological processes that individuals engage in over time, as they learn to adapt to the changes they encounter. Hulbert-Williams and Hubbard (2015) define adjustment as “the process of change and adaptation that occurs as the individual attempts to integrate cancer into their lives, whilst at the same time maintaining some sense of normality and psychosocial homeostasis” (p. 273)⁴. This definition of adjustment will be adopted for the current study.

² Please see extended introduction (section 1.1) for further details about head and neck cancer, its treatment and side effects.

³ Please see extended introduction (section 1.2 & 1.4) for further details about the psychological effects of head and neck cancer and psychological service provision.

⁴ Please see extended introduction (section 1.5) for further details about adjustment.

Psychological support may be required to facilitate the process of adjustment to living with head and neck cancer, however there is limited literature demonstrating the benefits of this (Anderson & Franke, 2001). Adjustment to any cancer poses specific and unique challenges as individuals “transition from “cancer patient” to “person”” (Stanton et al., 2005, p. 2608). Individuals with head and neck cancer may face a particularly difficult adjustment and rehabilitation period due to the importance placed upon physical appearance, ability, and general functioning within our society (Anderson & Franke, 2001). Furthermore, due to the quintessential functions affected by head and neck cancer, “generic cancer work” is likely to inadequately address the unique needs of these patients (Ziegler et al., 2004). The development of an adjustment theory for head and neck cancer would offer a framework to guide individual psychological interventions, and may also inform wider service provision.

Existing theories of adjustment

Existing cancer adjustment theories⁵ largely aim to explain the cognitive processes involved when patients attempt to navigate their adjustment to cancer. These theories include the Social-Cognitive Transition model of adjustment (Brennan, 2001), the Model of Restorative Well-Being (Hoffman, Lent & Raque-Bogdan, 2013; Lent, 2004), and the Cognitive Model of Adjustment to Cancer (Moorey & Greer, 2002, 2011). Consequently, the role of emotions within adjustment to cancer is somewhat neglected in the existing models. Furthermore, whilst the role of others is considered, it appears generally to be an adjunct to the theory, rather than integrated within it. It may also be argued that the existing models, in part, lack specificity to explaining the psychological adjustment to cancer, and may be applicable to any major life-changing event.

Rationale and research questions

The experience of head and neck cancer has been documented through exploratory qualitative research⁶, however there is a paucity of literature regarding adjustment to such threat on functional integrity and self-identity. Lang, France, Williams, Humphris and Wells (2013) conducted a metasynthesis of head and neck cancer patient

⁵ Please see extended introduction (section 1.6) for further details about existing adjustment models.

⁶ Please see extended introduction (section 1.3) for further details about the experiences of head and neck cancer patients.

experiences and identified a lack of knowledge and research around *how* patients make adjustments following their diagnosis and/or treatment (e.g., what strategies they use to cope with difficult thoughts, emotions and physical pain). Despite this, there are no current published studies within the field of psycho-oncology that explore *how* patients with head and neck cancer adjust. It is imperative to address this gap and provide an adjustment theory that may be used by Clinical Psychologists and a wide range for professionals (e.g. Clinical Nurse Specialists, Oncologists), to facilitate their understanding of how psychological difficulties may arise, and enable them to offer preparatory interventions about expectations with patients about the potential psychological effects and anticipated adjustment journey. Thus, this study aimed to answer the following question:

- How do patients adjust psychologically to the experience of diagnosis and/or treatment of head and neck cancer; what specific elements and processes are encompassed within this adjustment?

Method

Research design and participant recruitment

This study was undertaken from a critical realist position; a paradigm which seeks to develop deep understanding and explanation of social processes (McEvoy & Richards, 2006; Miles & Huberman, 1994). Grounded theory, undertaken from the framework and guidelines presented by Corbin and Strauss (2015), was utilised. Grounded theory is particularly helpful when existing knowledge is limited as it allows development of concepts and relationships that could not have been anticipated in advance (Strauss & Corbin, 1994)⁷.

Participants were recruited from three NHS Hospital sites and were initially approached by a member of their usual care team. Purposive sampling was used to recruit participants with varied experiences of head and neck cancer, e.g. in terms of time since diagnosis, or treatment received. Individuals were invited to participate in the study if they: (i) had an occurrence of head and neck cancer, either at present or in the past; (ii) were over 18 years old; (iii) were able to give informed consent; and (iv) were expected by their involved clinician to be in a stable condition for a period of 12 months (to be

⁷ Please see extended methodology (sections 2.1 & 2.2) for further details about study design.

adjusting to life with head and neck cancer, rather than end of life). Individuals were excluded if they were not fluent in English as it was anticipated that meaning and adjustment to such personal experiences may be lost in translation. The study protocol also allowed for participants to consent to be interviewed twice, at least three months apart⁸.

Thirteen participants were approached for inclusion in the study, all of whom consented to be interviewed; participant demographics are described in Table 1. One participant was not available to be interviewed within the timeframe of the study, therefore 12 participated. All were White British, two of whom reported current anxiety/depression and difficulty with emotion regulation. Four reported a history of mental health problems prior to HNC diagnosis: two reported depression, one reported depression and anxiety, and one reported bereavement difficulties. All participants were interviewed once; two in the presence of their spouse.

Data collection⁹

Individual audio-recorded semi-structured interviews lasting between 40 and 95 minutes were conducted by the first author (LC) either face-to-face (at a Hospital site (n= 5) or in the participant's home (n=6)), or via telephone (n=1). The initial interview schedule covered broad topics: participants' understanding of the term 'adjustment'; the adjustments they had made following their cancer experience; awareness of making such adjustments; challenges in making adjustments; and feelings evoked when reflecting on their adjustment. During the course of the study, the interview schedule was revised three times, becoming more focused as concepts emerged from the analysis. No appropriate adjustments to the interview format were necessary for any of the recruited participants. All interviews were transcribed in full for analysis.

⁸ Please see extended methodology (section 2.4) for further details about study sample.

⁹ Please see extended methodology (section 2.6) for further details about data collection.

Table 1. Participant demographics

Participant pseudonym (Gender)	Age	Head and neck cancer site	Time since diagnosis	Treatment type	Other experience of cancer	Support available	Access to psychology services
Walter (M)	65	Cheek	16 months	Surgery, Radiotherapy, Chemotherapy	Yes - Lung	Family	Yes – 6 individual sessions
Eve (F)	47	Thyroid	2 years	Surgery	No	Family, Friends, Peer group support	Yes – 23 individual sessions
Bruce (M)	35	Tongue	1 week	None at present - <i>Planned Surgery, Radiotherapy, Chemotherapy</i>	No	Family, Work Colleagues	No
Lawrence (M)	45	Tongue	5 years	Surgery, Radiotherapy	No	Family, Friends	Yes – 6 individual sessions
Sebastian (M)	52	Tonsil	2 years	Chemotherapy, Radiotherapy, Surgery	Yes - Lymph nodes	Family	Yes – 6 individual sessions 10 Group Mindfulness sessions
Raymond (M)	59	Throat	9 months	Chemotherapy, Radiotherapy	No	Family, Macmillan	No
Peter (M)	69	Throat	3 months	<i>Previous: Chemotherapy, Radiotherapy</i> Current: Surgery	Yes - Throat (recurrence)	Family	No
Alice (F)	65	Nasal & Sinus	22 months	Surgery, Radiotherapy	No	Family	No
Arthur (M)	55	Sinus & Eye	5 months	Surgery, Radiotherapy	No	Family, Friends	Yes – 5 counselling sessions
Marie (F)	71	Sinus & Eye	18 months	Surgery	Yes - Bladder	Family, Friends	No
Wendy (F)	70	Tonsil	9 years	Surgery, Radiotherapy, Chemotherapy	No	Family, Friends	No
George (M)	72	Tongue	14 months	Surgery	No	No one	No

Note. F, Female; M, Male

Data analysis

Transcribed interviews were imported into 'NVivo 11' (QSR, 2017), a computer software program compatible with grounded theory methodology¹⁰. The data were analysed using Corbin and Strauss' (2015) guidelines. Transcripts were initially coded sentence-by-sentence using an 'open-coding' strategy, aiming to identify and label important words and concepts contained within the data. 'In vivo codes' were used where participants' verbatim quotes offered the best description of a concept (Corbin & Strauss, 2015). Through constant comparative analysis, codes and concepts were grouped together to form more abstract concepts and categories. Axial coding was used to identify and outline proposed relationships between concepts. The data was revisited to verify concepts and relationships, and to identify a core category which was then integrated with other subsidiary categories, via plausible explanatory relationships, to form the basis of the theory¹¹. The model was shared with the final three participants, and a clinician working within the field for their comments and any suggested amendments. Memos and diagrams were used throughout the analysis process to aid theory development and remain working at a conceptual, rather than descriptive, level¹². A reflective diary was maintained for the duration of the study, and supervision was used regularly to facilitate reflexivity and awareness of any potential influences that the first author (LC) may exert on data analysis as a result of her assumptions and expectations¹³.

Quality evaluation

Corbin and Strauss' (2008, 2015; Strauss & Corbin, 1990) criteria for evaluating the quality and 'credibility' of grounded theory studies were applied to this research¹⁴. The criteria were continuously revisited throughout the study and the data and theory were checked against them; reflection and supervision were used to facilitate this process.

¹⁰ Please see extended methodology (section 2.7.1) for further details about use of computer software for qualitative analysis.

¹¹ Please see extended methodology (section 2.7.2) for further details about data analysis process.

¹² Please see extended methodology (section 2.7.3) for further details about use of memos and diagrams.

¹³ Please see extended methodology (section 2.7.4) for further details about reflexivity.

¹⁴ Please see extended methodology (section 2.8) for further details about quality evaluation.

Ethical considerations

Ethical approval was gained from an NHS Research Ethics Committee and the Health Research Authority and Research and Development departments at each research site. Prior to the interview, informed written consent was gathered, and participants received a verbal and written debrief after interview. Pseudonyms were assigned to each participant to ensure anonymity, and all identifiable data was held securely in a locked cabinet. All electronic data was encrypted with passwords¹⁵.

Results

Participants engaged in several processes when adjusting psychologically to head and neck cancer. Some processes were time-limited, though may be of recurrent episodic nature, and some were ongoing throughout the whole adjustment process. The adjustment trajectory largely mapped on to the cancer trajectory as the processes engaged in were somewhat dependent on the physical ability and wellness of participants. Whilst some effects participants were adjusting to were unique to head and neck cancer, the processes used to adjust to these did not appear specific to head and neck cancer.

The nature of adjustment

All participants described the nature of adjustment. Most described an active, long-term process which was ongoing, uncertain, fluctuating, and all-encompassing, including all aspects of life rather than being confined to cancer-specific effects:

“Everybody takes everything for granted and then when it’s took away and left with a disfigurement ..., you have to change everything in your life” – Arthur

Conceptualisations of adjustment as an active process of change were contrasted with concepts of ‘just carry on’ and ‘keep going’ to continue to function adequately. These contrasting concepts, appearing to ignore the changes that needed to be adjusted to, were described by participants who also described adjustment in actively-engaged terms, suggesting that adjustment is a complex, multi-faceted process (sometimes acknowledging and accommodating the challenges and sometimes attempting to carry

¹⁵ Please see extended methodology (section 2.5) for further details about ethical considerations.

on regardless).

Participants differed in their understanding of adjustment; some saw it as a “coming to terms” and “coping” with everyday challenges, whilst others saw it as aiming for returning to “normality”, or as close to normality as possible. Despite contrasting views, all participants seemed to regard adjustment as aiming for something to be different to how it is currently¹⁶.

Modifying your relationship to the changes cancer brings

All participants described an implicit relationship with the changes brought about by cancer. Changes encountered were as a direct result of the head and neck cancer or its treatment, and may have been physical and/or psychological. It was apparent that although the relationship to changes is enduring, its nature is modified as participants adjust. Participants initially ‘battled’ against changes within the acute stages (pre-treatment or immediately post-treatment), and later within recovery and rehabilitation stages, they learned to live with and alongside the changes. As this process was present throughout interviews, and encapsulates all other processes, it was deemed to be the core category. The processes through which the relationship may be modified are elaborated upon below¹⁷.

‘Survive mode’

Most participants viewed their initial stage of adjustment as simply getting through each day. The term “survive mode” was offered by Arthur during reflection on cancer treatment and initial recovery stage:

“You go into survive mode, well I did, and it was just, every day I’ve got to survive, every hour, and that’s what matters” - Arthur

In ‘survive mode’, participants seemed to focus on things they could not do, and/or were different and difficult. Changes were generally made because participants were physically no longer able to function as they had previously. This highlights the

¹⁶ Please see extended results (section 3.1) for further details about the nature of adjustment.

¹⁷ Please see extended results (section 3.2) for further details about the core category.

potential difficulty of engaging in psychological adjustments at this stage of acute illness and recovery.

Different strategies were used for getting through this stage, including taking one day at a time, aiming to get through small chunks of the day, compartmentalising their thinking, and setting small goals:

“Taking it either day by day, half day by half day, even down to hour by hour, ... just narrowing my vision down to as close as I needed to” - Lawrence

Not all experienced this initial phase as such a battle; four participants acknowledged the initial recovery period from their treatment, though it did not feature as a salient stage. The perceived degree of pain and dysfunction, caused by cancer treatments, may influence how this process and phase of adjustment is experienced by participants¹⁸.

Instrumental support from others

Gaining instrumental support from others (spouses, friends, and nurses) was a key process associated with “survive mode”. Participants reflected on being incapable of performing simple tasks for themselves, some relying heavily on others to fulfil different needs to keep them alive¹⁹:

“I was in hospital laying there, you know, I was being cared for, all I could do was draw on support from the nurses, from the doctors, from, obviously, family and friends that were visiting me. I couldn’t make any rational adjustments or decisions to do anything differently” - Sebastian

Several participants also explained the difficulty of understanding and retaining information provided. Most were accompanied by family members to appointments and described how this was beneficial in terms of discussing things later and checking they had understood or remembered information correctly:

¹⁸ Please see extended results (section 3.3) for further details about ‘Survive mode’.

¹⁹ Please see extended results (section 3.4) for further details about ‘instrumental support from others’.

“In any of the meetings I had with doctors and things, my wife was with me most of them. There are things that she would say afterwards, did you remember they said this? No. It’s very difficult to take it all in” – Lawrence

Making a choice

When reflecting on how they transitioned away from struggling against the effects, most participants described that once they started to feel better physically, they realised they did not wish to carry on as they had been. This seemed to be a conscious decision-making process of deciding what they wanted for themselves and making a choice to change something or to potentially remain unhappy. Seven participants described a ‘turning point’, at which this conscious choice to change occurred. Turning points arose from noticing one’s own emotional state, others’ reactions, the emotional impact on others, getting the ‘all clear’, and returning to work but struggling emotionally:

“My daughter ... she’s a Daddy’s girl and every time she’d come in [to hospital] she was getting upset, “when are you coming home?” ... I think that’s when I think everything changed and I thought, I’ve got to fight this” – Raymond

Conversely, one participant described coming to this realisation gradually, perhaps as a result of the gradual onset of her difficulties. How participants arrived at ‘making a choice’ and what their choice entailed varied. However, Bruce did not engage in this choice-making process, perhaps because he had not encountered dramatic changes as he had not commenced treatment at the time of interview. Therefore, this process may only be applicable following treatment²⁰.

Developing own understanding

A key process for all was developing one’s own understanding of a variety of aspects related to head and neck cancer experiences. Eight participants developed understanding from biological explanations as to why they are unable to perform certain functions and that these may not (or will not) return. Some described this information as invaluable as they benefitted from understanding *why*:

²⁰ Please see extended results (section 3.5) for further details about ‘making a choice’.

“Certain appointments I go to and somebody will explain something in more detail to me. So then you think, oh yes, I can see why that and I can see why I can’t do this for the reason” – Alice

While this process largely included understanding physical limitations, understanding of emotional and psychological experiences was also developed. This included why participants may feel short-tempered with others, struggle to cope emotionally with work demands, and the normality of struggling with emotions:

“Everybody’s said to me that, with what I’ve gone through, I’m going to have emotions like this, you know. But in my life I’ve never had those emotions so much... I think it [understanding] does [help] because I think if I didn’t, I’d be constantly depressed and down” – Arthur

Developing understanding appeared to be the central aspect which other adjustment processes built upon (discussed below). At times, understanding was developed to a practical level, and participants only attempted what was physically achievable. However, it was also used to counteract difficult emotions, such as frustration, as it provided participants with an explanation for their struggles. An improved understanding of their situation may afford patients the opportunity to approach challenges differently (discussed further in ‘making changes’)²¹.

Acceptance

Participants often engaged in a process of ‘acceptance’, facilitated by their understanding of their difficulties. Acceptance was utilised for many problematic experiences, including facial disfigurement, scars, difficulties with eating and swallowing, fatigue, pain, difficulties with speech, the need for a feeding tube, and other physical limitations.

Broadly, acceptance was used to feel less affected by sad, angry, and frustrated feelings related to not being able to get ‘back to normal’. Nine participants reflected simply needing to accept that “it is what it is” (Sebastian) and that there is “no alternative”

²¹ Please see extended results (section 3.6) for further details about ‘developing own understanding’.

(Peter) but to accept what has occurred. This suggests that for some, ‘acceptance’ may include an element of resignation and reflects a pragmatic thinking style. Acceptance was also discussed as a preferable alternative to continuing to fight and thinking what ‘ought’ to be happening:

“Choose your battles, there’s things you can’t change. So there’s no point in fighting too hard against those things because you get exhausted, nothing changes”
– Lawrence

Acceptance was viewed as an ongoing process, and several meanings of acceptance were used by participants simultaneously. Nevertheless, it seems that despite this variance in delineation of ‘acceptance’ and the process it represents, engaging in *an* ‘acceptance’ process resulted in the diminished impact of difficult emotions such as anger, sadness, and frustration²².

Talking with others

All participants engaged in talking with others, serving various functions at different times, for different participants. This included talking with medics, peers (other head and neck cancer patients with similar experiences), friends and family, and therapists. Participants also often described an implicit process of deciding what information to share with whom.

Conversations with medics were largely based around gaining knowledge which facilitated understanding of experiences and limitations (see above). Other aspects included knowledge about what to expect and what is ‘normal’ experience. The notion of ‘normal’ experience was important to four participants as they had struggled to understand why certain effects were being experienced; simply knowing that it was ‘normal’ even if they did not understand the reason was reassuring:

“It does help, yes, because you think that, as stupid as it sounds, you say to yourself, is this normal, why am I like this” – Arthur

²² Please see extended results (section 3.7) for further details about ‘acceptance’.

Talking within a therapeutic setting was also valuable and included learning about a psychological understanding of difficult emotional experiences; how these may build up and become difficult to manage and also strategies which may help to diminish this burden (practicing mindfulness was mentioned as a particularly helpful strategy). Talking also helped on a more general level to clarify participants' thinking about their struggles and experiences:

“I don't know whether just saying these things out loud and just getting them off your chest, whether it's just hearing me say them and your brain actually listening, going, OK, well you're talking rubbish now, aren't you?” – Lawrence

The function of talking with others was described as developing the participant's own understanding and to develop the understanding of others thus creating a shared understanding. However, there were contrasting views regarding whether talking to family and friends was helpful. Six participants actively chose not to talk to family and friends. Reasons included wanting to protect and not burden or worry others, wanting to avoid others' reactions, and feeling awkward as a result of others' reactions. Talking or not talking to others seemed to depend on the individual characteristics of the participant, and also the characteristics and relationship that the individual held with the participant²³.

Making changes

All participants reflected on making changes to the way they live their lives. Some changes involved practically approaching physical limitations and everyday life differently, and some were psychological changes, which included a shift in the relationship they held with themselves, their outlook, and life focus. Participants engaged in self-coaching; reminding themselves of the positive aspects of their lives, to 'keep going', to focus on achievements (no matter how small), and to not "wallow" in negative feelings. For three participants this also included exercising more self-compassion:

²³ Please see extended results (section 3.8) for further details about 'talking with others'.

“Recognising that it’s OK that I can’t do it. So being kind to myself, I suppose, is one of the key words I’ve pulled out of this, is don’t beat yourself up if it’s not going right, just try again another time” – Sebastian

Practical strategies included engaging in rehabilitation (e.g. physiotherapy, speech and language therapy), keeping occupied with activities (e.g. music, physical activity, seeing friends and family, playing games), avoiding certain foods, and ensuring easy access to water (to assist with swallowing and dry mouth). Participants also managed their time differently; allowing themselves more time to complete tasks and allowing themselves to take ‘time out’ when they felt they were struggling:

“I take myself upstairs, I put one of my discs on that I got in the mindfulness groups that I’ve done, and I bring myself away. So I’ll do like a body scan and it sort of works your way through and brings me out” – Eve

Fatigue was also managed via practical strategies. The predominant strategy was breaking down tasks into small manageable chunks and taking breaks between them, though participants acknowledged that making this change was a challenge.

Seven participants described a changed outlook and focus in life, and/or had increased their appreciation of aspects of life. This included not becoming stressed about ‘unimportant’ things, thinking more about what they say, not becoming as angry with others, and focusing on enjoying life *now*. Participants described realising that they had ‘taken things for granted’, now slowing down to appreciate the present and their fortunes (having a family, job, home):

“You live your life and over the years it gets a million miles an hour and then all of a sudden, bang, this comes along and stops all that. But then you look out and you see the grass and the trees and you think, and when you think you could have lost all that, you really appreciate these things in life” – Arthur

All participants made changes, though to differing degrees. Some made changes in all areas discussed above, whilst some made mostly practical changes to continue to live in

a way that is satisfactory to them and disagreed with the concept of changing their outlook²⁴.

Redefining or regaining normality

A return to, or a redefining of normality, seemed to occur for all participants, albeit in different ways. A return to normality included resuming aspects of previously held roles, or everyday life, that participants valued. This included pastimes such as shopping, volunteering, or hiking; returning to work; helping around the house; and beginning to socialise again. The return of some of these valued aspects was reflected upon as both an automatic response to feeling better, and also as a conscious effort to return to them. Some participants identified the ongoing presence of their head and neck cancer effects, thus leading to a sense of *redefining* normality e.g. needing constant access to water, living with fatigue, living with dips in mood. Participants noticed that some enjoyment had returned, perhaps as a result of redefining ‘normality’.

Redefining or regaining normality was a process present for all participants. For those who acknowledged that ‘back to normal’ wasn’t possible due to the changes they had experienced, redefining normality allowed them to feel satisfied with how they were living their lives. For those who did not perceive normality to be altered, regaining normality was achieved by re-engaging with previously held roles and treasured activities and hobbies²⁵.

Barriers to progress

Most participants perceived barriers that made adjusting more difficult, or hampered progress. These included the ongoing and constant effects of head and neck cancer, awkwardness from other people, loss of confidence, playing the “what if” game or questioning where cancer “came from”, and reactions from others. Participants highlighted that other people’s reactions and expectations of them were particular barriers. They described how others did not understand the ongoing effects and expected them to be ‘alright’ (often used synonymously with ‘back to normal’) following treatment:

²⁴ Please see extended results (section 3.9) for further details about ‘making changes’.

²⁵ Please see extended results (section 3.10) for further details about ‘redefining or regaining normality’.

“Even my mum at one point said, well you’ve had it took out now, so you’re OK... So it was sort of trying to get them to understand that, yes, they took it away and I know they’ve took it away, but they couldn’t understand the bits afterwards” – Eve

The fluctuating nature of the ongoing effects and physical limitations required continuous effort to adapt to, and to comprehend why they occurred. Ongoing pain and fatigue hindered making and maintaining changes and had the potential to initiate a return to “survive mode”, due to the resources required to overcome them. Lawrence described how returning to working fulltime too soon resulted in extreme tiredness (fatigue), and he reverted back to simply surviving each day:

“I very quickly got back to working full time, even though I shouldn’t have been... literally, wiped me out. I spent most weekends just recovering, I’d got no stamina left, I’d got no reserves of anything. So I’d go to work; work all day, come home, try and eat something, go sleep, wake up, repeat” – Lawrence

These various barriers to progress emphasise the complexity and difficulty of adjusting to head and neck cancer, and the many factors that may influence this process. Both visible and non-visible effects were reflected on as barriers and included physical issues and interpersonal difficulties. This further highlights the importance of feeling physically ‘well’ and others’ understanding of the effects in facilitating participants’ psychological adjustment, and the potential detrimental effect this may have if they are not present²⁶.

Managing emotions/distressing thoughts

Managing emotions and distressing thoughts (e.g. recurrence fears) was reflected on by most participants. Fundamental to managing emotions such as frustration, upset, and anger was the acknowledgement that the experience of them was normal and to be expected. This facilitated validating emotional experiences, and allowing the experience of emotions whilst not allowing emotions to escalate too much (although what determined ‘too much’ was not well understood or defined):

²⁶ Please see extended results (section 3.11) for further details about ‘barriers to progress’.

“I think every now and again you’ve got to have a little pity party” – Marie

Most participants engaged with their emotions in some way, however, sometimes participants chose to “shut down” (Alice) from emotions and avoid certain situations. How participants managed emotions seemed to depend on previous coping strategies and personality style:

“I tend to be a sort of person that shuts down within myself, and I tend to, you know, put up a wall around me ... I tend to do that instead of getting emotional” – Alice

Distressing thoughts included fears of recurrence. These were managed through positive self-talk, including reminding themselves that they have been treated and have been told the cancer has been removed (or killed), and that they have dealt with it once and therefore are capable of dealing with it again. Seeking medical advice and reassurance was also a common strategy for managing recurrence fears. Practicing mindfulness skills (often discussed in the context of focusing on the present, putting fears to the back of the mind) was also reflected on as a helpful strategy for managing these thoughts:

“Mindfulness ... if it’s back it’s back and there’s, I just think, there’s nothing I can do to stop it, prevent it, I can’t, you know, miraculously say, don’t come in my body anymore, so why live every day thinking that everything’s cancer” – Eve

Management strategies varied; however, engaging in this process appeared to be an important aspect that spanned from diagnosis to years after treatment completion. Two participants (Peter, George) reported minimal emotional reactions or distressing thoughts and therefore did not perceive it necessary to engage in this process²⁷.

²⁷ Please see extended results (section 3.12) for further details about ‘managing emotions and distressing thoughts’.

Putting things into perspective

All participants described ‘putting things into perspective’ throughout their adjustment. This included acknowledging negative effects and their own mortality, but overall remaining grateful for their survival. Concepts of ‘I’m still here’ and ‘others are worse off’ prevailed within this category. Difficult experiences (physical limitations and disfigurement) were often reflected on as a ‘cost’ of survival:

“They said you could possibly lose your eye, the sight in your eye, and that really upsets you. Well it did me, the thought of not being able to see at all. And then I got angry with myself then and I thought, you know, but again, why get angry about it because if you’re alive it’s everything” – Arthur

Participants described feeling unlucky for their cancer occurrence but lucky that it had been found and successfully treated. Participants also considered the alternatives, for example Alice reflected on the occurrence of her cancer in later life – acknowledging its current restrictive effects but also how much more disruptive it would have been if it had occurred earlier:

“At this age I’ve got this but if it had happened when I was say thirty, it would have made a whole difference and it would have impacted on your family life in a big way, much more than now” – Alice

The value participants placed on their continued life was often used to mitigate, or diminish, the impact of their physical limitations, disfigurement, and negative emotions. While valuing life was key, participants also varied in how they engaged in other aspects of “putting things into perspective”, for example, by focusing on retained abilities and life elements, and being grateful for what has been retained²⁸.

Developing a grounded theory model

We developed a model which visually represents how each of the processes described above relate to one another (see Figure 1). The model of psychological adjustment to head and neck cancer is presented with a visual representation of the cancer trajectory to

²⁸ Please see extended results (section 3.13) for further details about ‘putting things into perspective’.

provide insight into how the physical recovery process may map onto, and influence, psychological adjustment. This model is a synthesis of the concepts and categories generated inductively from the data provided by participants in this study. It is acknowledged that the model may also be applicable to other cancer participants, and potentially sufferers of chronic illnesses, though this would require further research.

In summary, the core process underpinning the model relates to participants modifying their relationship to the changes that cancer brings; from battling against effects, to learning to live alongside the changes. While acutely unwell, participants may enter a “survive mode” where they may “battle” against physical limitations, during which they require instrumental support from others. Once acute effects diminish, participants make a choice to change their approach. Their own understanding of their experiences and difficulties is developed through talking to others, which may facilitate acceptance of the current situation. Participants may then make changes to increase their self-compassion, alter their approach to practical problems, or their outlook and life focus; they may then engage in a process of redefining or regaining normality. Throughout, participants put things into perspective and manage their emotions and distressing thoughts. Barriers to progress may hinder any of these processes and may direct participants back to ‘survive mode’. Initially, ‘acceptance’ was placed at the centre of the model, however, following consultation with a clinician working in the area it was considered that ‘developing own understanding’ was more of a central theme. The centrality of this theme was justified as it appeared to have primacy over ‘acceptance’ such that once an individual had some understanding of their experiences and limitations, they were then more able to engage in an ‘acceptance’ process – the model presented in Figure 1 reflects this amendment. This amendment also allowed the ‘developing own understanding’ theme to be linked to ‘talking with others’; this appeared to be linked as a way of helping to develop understanding, and also once understanding was developed individuals were then more able to talk to others (i.e. family and friends).

As the study reflects, head and neck cancer patients are not a homogenous group. Therefore, the extent to which participants engage in each of the processes within the model may vary. The findings of this study suggest that patients may engage in all aspects of a process, though for some this may be for a limited time. Indeed, some

exceptions were also found as some participants did not engage in all processes. It is possible that the extent to which patients engage in each process is influenced by the severity and duration of physical limitations and disfigurement.

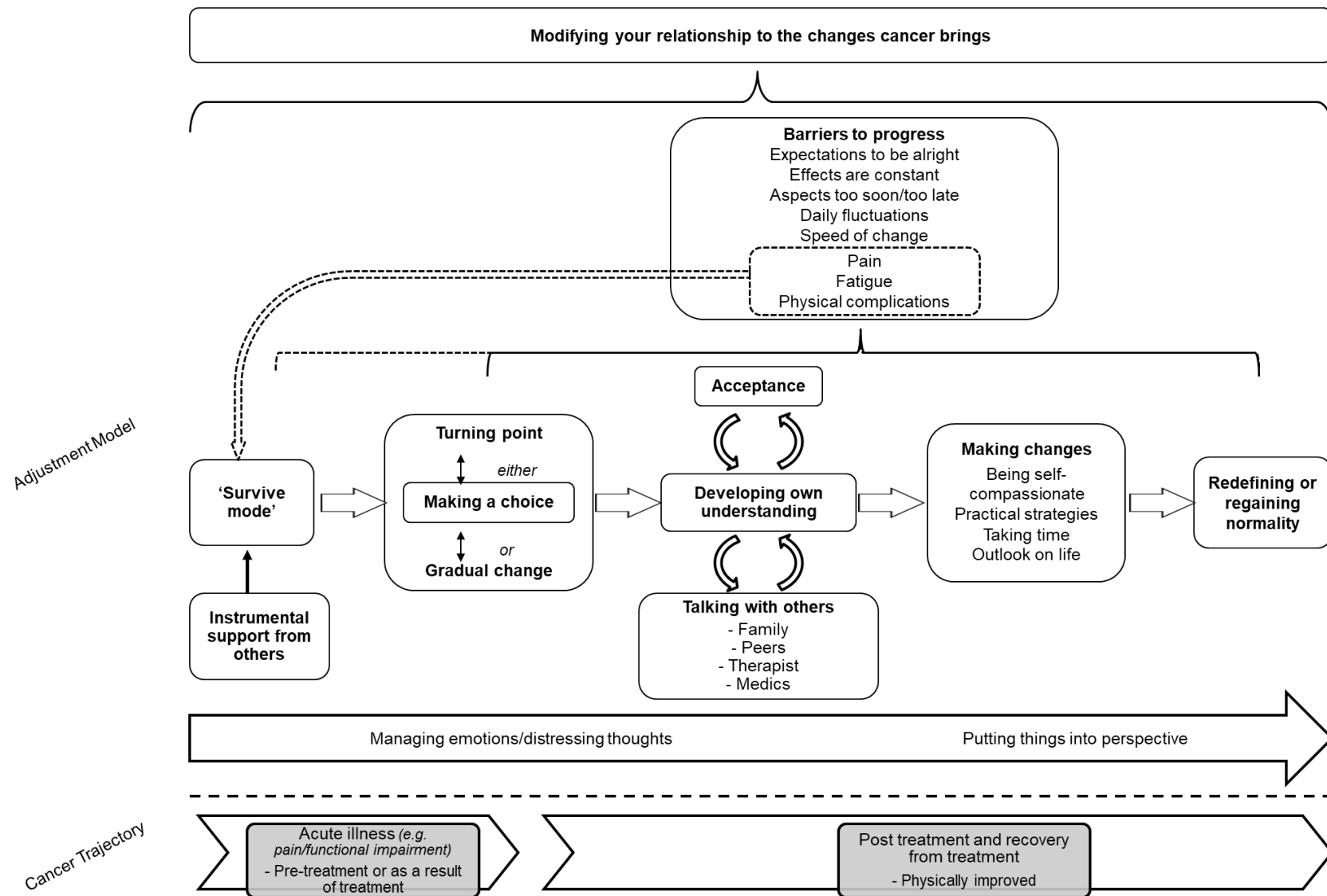


Figure 1. A model of psychological adjustment to head and neck cancer.

Sharing the model

The grounded theory model was shared with the final three participants (George, Marie, and Wendy). They appeared to understand and relate to most processes, however, there were contrasting views regarding how much they may have engaged in each (despite this they did not suggest making any changes to the model). For example, George and Wendy did not perceive themselves to have struggled initially with battling against changes brought about by cancer, and therefore did not identify with the ‘survive mode’ aspect of the model. They hypothesised that this may have been due to not having experienced (or remember experiencing) physical pain or feeling unwell:

“I didn’t have any problem recovering because, as I say, I never had any pain or anything like that” – George

Marie and Wendy identified with the temporal processes within the model, stating their understanding of how they linked together. However, their time scales differed; Wendy identified with the processes, but perceived them to be confined to the six month period in which she completed treatment. Marie attributed her swift journey through adjustment to only needing to recover from surgery, and anticipated that she may have needed to engage more if she had received multi-modality treatment:

“I would say that it probably all fits with me because all these things along here is getting through that treatment, that’s what I see that’s meaning. So I suppose, yes, at the time, I suppose I would have fitted all that” – Wendy

“I can see where you’re coming from and how it flows through. And, as I said, I’ve just been very, very lucky, because I didn’t have to have chemo, I didn’t have to have radiotherapy. If I’d had them, then it would have been a different story” – Marie

Thus, the treatment modality and severity of physical consequences of treatment could influence the extent to which patients engage in particular processes.

Discussion

This study aimed to develop a theory to provide an understanding of how patients adjust psychologically to head and neck cancer. Participants engaged in various processes throughout their adjustment. Some processes were time-limited, though may be returned to at a later date, for example ‘survive mode’, and some were enduring throughout adjustment, for example, ‘putting things into perspective’. The processes relevant to participants appeared to be dependent upon their physical recovery, and the extent of their engagement in each process was influenced by the perceived degree of physical limitation or impairment, extent of facial disfigurement, emotional reaction to changes, and responses from others.

The initial phase of ‘survive mode’ indicated that participants were required to ‘battle’ against their physical limitations, and pain, to survive. This highlights the potential difficulty of engaging in psychological adjustments at initial stages of acute illness. This may be conceptualised in terms of Maslow’s (1943, 1970) hierarchy of needs, which suggests that higher-order needs emerge when basic needs such as food and safety are sufficiently met²⁹. In most instances, for their needs to be met, participants required social support from others.

Participants relied on others for social support *throughout* adjustment, though this took different forms at different points, as reflected by ‘instrumental support from others’ and ‘talking with others’. Social support may be categorised as three different forms: emotional, instrumental, and informational support (House, 1981). Several studies have previously investigated the effects of social support on cancer progressions (Nausheen, Gidron, Peveler, & Moss-Morris, 2009; Rose, 1990; Usta, 2012). Within our study, it was clear that instrumental support (providing tangible aid, e.g. assistance with household chores) was necessary and beneficial to aid most participants in their initial recovery due to their physical limitations. These findings are opposite to that found in other studies, which conclude that receiving instrumental support is associated with lower quality of life and higher depression scores (Bloom, Stewart, Johnston, Banks & Fobair, 2001; Sultan, Fisher, Voils, Kinney, Sandler & Provenzale, 2004). However, our findings agree with other studies reporting that availability and provision of emotional support was considered universally helpful (Bernad, Zysnarska & Adamek, 2010;

²⁹ Please see extended discussion (section 4.1) for further details about fulfilling needs.

Hegleson & Cohen, 1996; Rose, 1990). Informational support was considered to play a key role in ‘developing own understanding’ within the current study, though was also described as difficult to ‘get right’ regarding the amount of information provided. The source of informational support has been highlighted in previous studies as important since it was considered beneficial when received from medical professionals, and unhelpful when provided by family or friends (Bernad, et al., 2010; Hegleson & Cohen, 1996; Rose, 1990).

Social support plays an important part in several processes contained in our model, and several authors stress the importance of tailoring the type of support provided to the situation and personal characteristics of the patient (de Leeuw, de Graeff, Ros, Hordijk, Blijham & Winnubst, 2000; Semmer, Elfering, Jacobshagen, Perrot, Beehr & Boos, 2008). However, little is known regarding the mechanisms through which social support may provide beneficial effects – this requires further research. Nevertheless, the current study highlights the need for accurate, timely information for head and neck cancer patients to aid their psychological adjustment³⁰.

Acceptance was identified as a process participants frequently engaged in. It is acknowledged that receiving psychological therapy may have influenced how some participants viewed ‘acceptance’. However all participants used the term ‘acceptance’; many spontaneously before it was incorporated into the interview schedule. Engagement in ‘acceptance’ is commonly reported in qualitative studies investigating the lived experience of head and neck cancer (Ganzer, Rothpletz-Puglia, Byham-Gray, Murphy & Touger-Decker, 2015; Semple, Dunwoody, Kernohan, McGaughan & Sullivan, 2008). Acceptance plays a central role in Acceptance and Commitment Therapy (ACT; Hayes, Stroschal & Wilson, 2011), and is described as an active process which involves making space for, and not fighting against difficult private experiences (Harris, 2009). In respect to this definition of acceptance, the ‘acceptance’ processes identified in qualitative studies may not be considered as acceptance, since they appear to include elements of tolerance, reluctance, and “stoic acceptance” (Semple et al., 2008)³¹. Therefore the change process facilitated by ‘acceptance’ as described in these

³⁰ Please see extended discussion (section 4.2) for further details about social support.

³¹ Please see extended discussion (section 4.4) for further details about acceptance.

qualitative studies is unknown. The current study was not in a position to explore these intricacies and therefore offers limited insight into the meanings assigned to participants' use of 'acceptance' – future research may help to address this³².

'Putting things into perspective' was a process all participants engaged in throughout their adjustment and was described as a key aspect. This has been reported in several other studies in which disfigurement or functional difficulties have been framed by patients as the 'price to be paid' for being alive, or cured (Costa, Nogueira, de Souza Lima, Mendonça, & Leles, 2014; Semple et al., 2008). Some studies investigating coping styles have labelled this as 'fighting spirit', which is often recognised in the literature as an active, helpful, coping strategy, encompassing a positive-attitude and perception of cancer as a 'challenge' (Semple et al., 2008; Watson et al., 1988). However, Hulbert-Williams, Storey and Wilson (2015) suggest that 'fighting spirit' may not always be helpful since its vocabulary may simply be used to appease others and convey positivity without being an accurate description of the emotional experience. However, within the current study this approach of considering the alternatives (e.g. death) and remaining grateful for what was retained appeared to be a beneficial one. It would be pertinent for future research into coping styles to explore this further³³.

One surprising aspect of the findings was that there did not appear to be a unique adjustment process for head and neck cancer. A unique adjustment process was anticipated due to the combination of symptom profile, functional sequelae, and potential for prominent visible differences within this population. Whilst specific changes and challenges were present as a result of head and neck cancer (e.g. difficulties in swallowing, eating, speaking), and required psychological adjustment, the processes found to aid this adjustment may be expected to be found within adjustment to any cancer type, for example, acceptance and talking with others³⁴. Our findings also suggest that adjustment to head and neck cancer encompasses many aspects of life and is not confined to simply adjusting one or two discrete aspects, and therefore any

³² Please see extended discussion (section 4.9) for further details about implications for future research.

³³ Please see extended discussion (section 4.5) for further details about coping strategies.

³⁴ Please see extended discussion (section 4.6) for further details about how the proposed model relates to existing cancer adjustment models.

intervention aimed at facilitating adjustment must consider this. The complexity and extensive effects of head and neck cancer have also been reported in other studies, highlighting that this is a common finding for this patient group (Henry et al., 2014; Röing et al., 2009; Semple et al., 2008).

Strengths and Limitations

The key contribution offered by this study is the understanding of how participants may adjust, which is grounded in patient data. In comparison to existing adjustment models (Brennan, 2001; Lent, 2004; Moorey & Greer, 2002, 2011), which were developed theoretically from existing literature, our model was developed inductively from interview data and offers a hypothetical process of how an individual may engage in different processes, at different times throughout their cancer trajectory. Limitations of our study include a small sample which may limit the transferability of the model, however, that the model is applicable to a heterogeneous sample increases its transferability. This study also excluded participants who may have received a ‘terminal’ diagnosis, thus when applying these findings to other settings it would be important to not assume that the model would be applicable to participants with terminal cancer diagnoses. Additionally, participants were interviewed retrospectively, therefore subsequent experiences and thoughts may have influenced their accounts of their adjustment experiences. Although the study was designed to interview participants at more than one time point, due to the time constraints of the study this was not possible to complete; it would be beneficial in future research to follow up participants using longitudinal designs. It is also acknowledged that those interviewed in the presence of spouses may have been reluctant to discuss some particular difficulties, especially regarding relationships throughout their adjustment. However, the presence of their spouse was requested by participants, therefore it is considered that this may not have been a salient issue for these participants³⁵.

Clinical Implications

The all-encompassing nature of head and neck cancer and adjustment suggests a need to think broadly about interventions aimed at facilitating psychological adjustment. The

³⁵ Please see extended discussion (section 4.7) for further details about the study’s strengths and limitations.

complexity of the head and neck cancer experience is highlighted by Semple et al. (2008), who identified that one area of difficulty experienced by patients often impinged on other aspects of daily life. Adjustment, therefore, must be considered as a whole inter-connected complex network rather than being made up of discrete aspects and entities which may be intervened with separately. Any intervention focusing purely on cancer-related aspects is likely to be insufficient to allow patients to make the changes necessary to adjust. At present there is limited evidence supporting the effectiveness of psychological therapies to address quality of life issues which may stem from difficulties in adjustment to head and neck cancer (Calver, Tickle, Moghaddam & Biswas, 2018).

The core category of ‘modifying your relationship to changes cancer brings’ has clear clinical implications for psychological interventions aimed at facilitating adjustment. ACT focuses on altering the relationship that an individual holds with their experiences, rather than on changing the content of their experience (Hayes et al., 2011). Consequently, ACT may provide a good fit for psychological interventions facilitating adjustment to head and neck cancer since this focus fits well with the core category of “modifying your relationship with the changes cancer brings”.

This study also identified a need to potentially prepare patients for the long-term effects of head and neck cancer and its treatment, and the prolonged recovery period they are likely to experience. Owing to this, it would be beneficial for services to integrate psychological provision early within the care trajectory of patients. Psychologists are well-placed to start these preparatory conversations with patients, helping to normalise the experience of adjustment difficulties and provide further psychological support if necessary. The model may also provide a psychological understanding to other members of the care team (e.g. Clinical Nurse Specialists) so that they may also feel confident in having these conversations with patients³⁶.

Conclusion

This study has contributed to our understanding of the processes patients may engage in to adjust psychologically to head and neck cancer. We developed a psychological model

³⁶ Please see extended discussion (section 4.8) for further details about the clinical implications.

of adjustment, grounded in patients' experiences, which acknowledges the diverse experiences each patient may have. Modifying the relationship held with the changes brought about by cancer played a key role in adjustment; from *fighting against* the changes and effects, to learning to *live alongside* them. The findings also highlighted the importance of considering the global impact of head and neck cancer and that all aspects of life must be adjusted; adjustment is not confined to the elements altered or affected by cancer. Surprisingly, the findings also highlighted that whilst some problems encountered by head and neck cancer patients may be unique to this cancer type, the processes in which they engage to adjust to these may be similar across other cancer types and chronic illness. The findings provide a number of implications for clinical practice and future research.

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EXTENDED PAPER

Chapter 1. Introduction

1 Extended Introduction

1.1 Head and Neck Cancer

Head and Neck Cancer (HNC) is an umbrella term describing cancers that occur in the oral cavity, pharynx (throat), larynx (voice box), paranasal sinuses, and salivary glands (Figure 2). Cancers at different sites within the head and neck have different courses and histopathology, though the vast majority are squamous cell carcinomas (Mehanna, Paleria, West & Nutting, 2010). Tumours originating in the eye, brain, or oesophagus (gullet) are not included under the HNC umbrella (Mehanna et al., 2010).

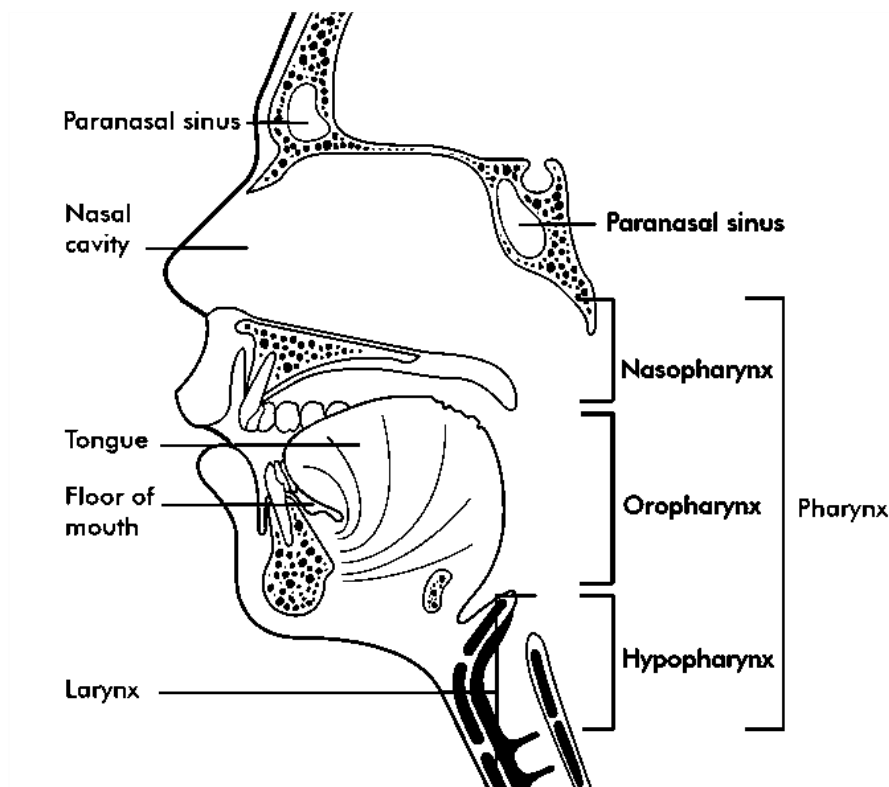


Figure 2. Anatomy of the head and neck (Macmillan, 2015).

1.1.1 Epidemiology

Worldwide, HNC accounts for approximately 930,000 cases and 380,000 deaths annually, making it the sixth most common cancer type (Global Burden of Disease Cancer Collaboration, Fitzmaurice & Allen, 2017). In Europe, HNC was estimated to account for 139,500 cases and 63,500 deaths in 2012 (Ferlay et al., 2013). The majority of HNCs occur in older individuals, with 98% of HNC diagnoses occurring in individuals over the age of 40 years, and 50% in individuals over 60 years (Mehanna et al., 2010). HNC is also far more common in males than females (Vigneswaran &

Williams, 2014). In 2012 in Europe, 79% of cases of HNC occurred in males (Ferlay et al., 2013). Across Europe the 1-year survival rate from HNC is estimated at 68.8% and a 5-year survival rate as 39.9% (Gatta et al., 2015). From an examination of the global incidence and mortality trends, Gupta, Johnson and Kumar (2016) report that HNC is expected to increase globally, not only in males, but also in females and the younger population (Gupta et al., 2016).

A diagnosis of HNC is confirmed by the histology of a biopsy taken from the primary cancer site (Mehanna, et al., 2010). Once a diagnosis is confirmed, the cancer is staged using physical examination by a head and neck surgeon and radiological assessments (MRI or CT scans) (Marur & Forastiere, 2008). The stage assigned to a cancer describes its size, whether it has spread to any lymph nodes, and whether it has spread beyond its primary site; HNC is staged using the TNM (Tumour Node Metastases) classification system (Macmillan, 2015). If a cancer has spread beyond its original site, it is said to be metastatic. Stage I or II cancers are relatively small primary tumours which have not spread to nodes – these are described as early/local, or locally advanced (Macmillan, 2015; Pfister et al., 2011). Stage III and IV cancers are described as advanced and include cancers which have invaded underlying structures and nodes, or have spread to other parts of the body (Macmillan, 2015; Pfister et al., 2011). More advanced TNM stage cancers are associated with poorer survival rates (Pfister et al., 2011). The majority of HNC cases are diagnosed when the cancer is in advanced stages; this delay in diagnosis and treatment is a major reason for patient mortality (Gatta et al., 2015; Nigro, Denaro, Merlotti, & Merlano, 2017).

1.1.2 Risk Factors

The causes of HNC are not well understood, however, epidemiological studies have identified several factors that, whilst not causal agents, are associated with increased probability, or risk of HNC occurrence (Dobrossy, 2005). These factors include tobacco use, high alcohol intake, dietary deficiencies, poor oral hygiene, and genetic predispositions (Dobrossy, 2005; Mehanna et al., 2010). Additionally, several viral infections have also been linked to an increased occurrence of HNC, namely the human papillomavirus (HPV) and the Epstein-Barr Virus (EPV) (Dobrossy, 2005; Mehanna et al., 2010). It is noted that HPV-related HNC's generally appear in younger individuals

(40-50 years old) who do not necessarily report engaging in the usual risk factors (Mehanna et al., 2010).

1.1.3 Treatment and Side Effects

Cancer treatment is recommended to start promptly following diagnosis; data from NHS England reported that 96% of individuals with HNC started their cancer treatment within 31 days of initial diagnosis (Samuels, Dai & McDonnell, 2017). Curative treatment for HNC typically includes surgery, radiotherapy, chemotherapy, or any combination of these treatment modalities. Surgery is the standard treatment for early stage HNCs, often with radiotherapy as an adjuvant treatment (Argiris, Karamouzis, Raben & Ferris, 2008; Nigro et al., 2017). Concurrent, multimodality treatments have been shown to be more efficacious in patients with advanced HNC, however, the adverse side effects are often more numerous and severe in these combined treatments (Bernier et al., 2004; Cooper et al., 2004; Gatta et al., 2015).

During surgery, a specialist surgeon will remove the tumour and any affected lymph nodes. Depending on the site of the cancer, reconstructive surgery may also be performed in which a ‘flap’ of tissue is taken from another part of the body (often arm or thigh) and is used to replace the tissues that have been removed (Macmillan, 2015). Reconstructive surgery is frequently conducted when the tissue to be removed is important for functions such as speech or swallowing. The outcomes of surgery and reconstruction can vary greatly depending upon the site, size, and type of reconstruction. However, disfigurement, voice loss or disturbance, difficulty eating and swallowing, pain, and limited shoulder mobility are all commonly cited effects of HNC surgery (List & Bilir, 2004; Macmillan, 2015). A feeding tube (which is often surgically inserted into the stomach through the abdomen) is sometimes required whilst the surgery site heals and recovers (Macmillan, 2015).

Radiotherapy uses high energy rays to destroy cancer cells (Macmillan, 2015). This is directed specifically at the tumour area to minimise the effect of radiation on healthy tissues, however, radiation effects are commonly observed. The effects of radiation on normal tissues (and cancerous cells) can result in side effects such as loss of taste, dry mouth (xerostomia), hoarse voice, thick and sticky saliva, dental problems, pain (including mucosal sensitivity; a burning sensation in the mouth), changes in

appearance, and difficulties with eating and swallowing (Ganzer et al., 2013; List & Bilir, 2004; Macmillan, 2015).

Chemotherapy uses anti-cancer drugs (cytotoxic) to destroy and damage cancer cells (Macmillan, 2015). Chemotherapy drugs are usually given intravenously though they can also be given in tablet form. Due to the nature in which they work, chemotherapy drugs circulate within the bloodstream and may target cancer cells throughout the body (Macmillan, 2015). Whilst chemotherapy used in conjunction with radiotherapy may minimise the disfigurements caused by surgery, it can impact on quality of life (QoL) and may potentially intensify the effects of radiotherapy described above (List & Bilir, 2004).

Radiotherapy and chemotherapy are often used as adjuvant treatments to surgery, though they may also be used alone when surgery is not a viable option, either in the interest of organ preservation or due to the tumour being located at an inoperable site (Marur & Forastiere, 2008). The increased efficacy of HNC treatments has come at the cost of increased acute and late adverse effects of treatment (Murphy, Gilbert & Rider, 2007). The late effects of treatments are often less overt and may be overlooked, however, they can profoundly affect a patient's QoL following HNC treatment (Murphy, Gilbert, Cmelak & Rider, 2007a). It is reported that some late effects may impact on a patient's ability to work, engage in daily tasks, or to care for themselves, which may consequently alter their social roles (Murphy, Gilbert & Ridder, 2007b). Taylor et al (2004) reported that 52% of patients who were in work before their HNC diagnosis were subsequently rendered disabled as a result of their cancer treatment, with pain as a major predictor of disability.

1.2 Psychological Effects of Head and Neck Cancer

1.2.1 Prevalence of Psychological Distress

Patients with HNC are reported to be prone to psychological distress, both immediately after diagnosis and during treatment (Humphris & Ozakinci, 2006). Psychological distress in HNC patients has been linked to image disturbance, functional difficulties, threatened self-image and confidence (loss of normal facial appearance, speech or communication, and taste), and stigma (Kugaya, Akechi, Okamura, Mikami, &

Uchitomi, 1999; Lebel et al., 2013; Ziegler, Newell, Stafford, & Lewin, 2004). The presence of anxiety and depression issues in HNC patients impacts negatively on the quality of their survivorship, morbidity, and mortality (Archer, Hutchison & Korszun, 2008; Murphy et al., 2007b).

Psychological distress may range from common feelings of vulnerability, sadness, and fears, to symptoms of anxiety and depression that could become difficult to cope with. Psychological distress is reported to be significantly higher in HNC patients than in other cancer patients, with prevalence estimations of 35% (Singer et al., 2012; Zabora, Brintzenhofesoc, Curbow, Hooker & Piantadosi, 2001). Specifically, the prevalence of depression has been reported as 37-39%, and anxiety ranges from 27-44% in HNC patients (Shiraz, Rahtz, Bhui, Hutchinson, & Korszun, 2014; Veer, Kia & Papesch, 2010). Shiraz et al. (2014) also report a prevalence of 12% for acute stress disorder in HNC patients. Interpersonal difficulties within close relationships have also been reported and are hypothesised to be a result of feelings of reduced attractiveness, lower sexual desire, and decreased ability for verbal communication and facial expression (Smith, Shuman & Riba, 2017).

It has been suggested that many patients with HNC undergoing radiotherapy have symptoms indicative of psychological distress (depression and anxiety) prior to cancer treatment, and that this number increases when treatment commences (Chen et al., 2009; Neilson et al., 2012). Specifically, it has been observed that depression increases during treatment then decreases at follow-up, whereas, anxiety may decrease during treatment and increase at follow-up (Neilson et al., 2013). One hypothesis for this may be that patients struggle with the side-effects of radiotherapy and thereby develop depressive symptoms which dissipate as the side-effects also diminish. Additionally it may be hypothesised that anxiety decreases during treatment as a result of feeling that the cancer is being treated/killed, and this may return once treatment finishes, due to anxieties about treatment having been successful and recurrence fears. It was noted also that participants generally didn't report histories of mental health problems, suggesting that the diagnosis of cancer may be influential in the development of psychological difficulties (Chen et al., 2009).

Many factors may influence the psychological distress experienced by patients with HNC, including fear of recurrence, QoL, self-care behaviour, personality, advanced tumour stage, coping strategies, and social support (Aarstad, Belsland & Aarstad, 2012; Humphris & Ozakinci, 2006). Specifically, coping by disengagement (e.g. avoidance, distancing, and isolation) and coping by problem-solving is directly associated with greater distress (Aarstad et al., 2012; Morris, Moghaddam, Tickle & Biswas, 2017). Deno et al. (2012) found that good self-efficacy can counteract and protect against the effects of social or emotional distress, though the relationship between social support and distress is inconsistent e.g. social support from friends is associated with lower social distress and higher emotional distress. Conversely, social support from family was not seen to impact upon social or emotional distress, though patients may feel more supported simply by the presence of family members living with them. Stigma has also been demonstrated to be significantly correlated with depressive symptoms and feelings of shame due to HNC being linked to risk-related behaviours (e.g. smoking and drinking), however, the experience of stigma in HNC is less common than the general literature has suggested (Lebel et al., 2013). These surprising findings have been hypothesised to result from a general lack of awareness (from both the public and HNC patients) that alcohol consumption and smoking increases the risk for HNC, compared to other cancers such as lung cancer (Lebel et al., 2013; Viswanathan & Wilson, 2004). This may therefore result in less blame being assigned to the HNC patient, and subsequently a reduced experience of stigma.

The use of self-report tools, often relied upon in studies examining the psychological difficulties encountered by HNC patients, has been criticised as they do not provide sufficient information to determine psychiatric diagnoses and can only be suggestive of clinical levels of distress (Murphy et al., 2007b). Furthermore, several studies report many symptoms of anxiety and depression in HNC patients even though these do not always reach clinical cut off levels (Archer et al., 2008; Humphris et al., 2003).

1.2.2 Body Image Concerns

Body image difficulties are reported to extend beyond simply concerns about physical appearance and disfigurement to include functional loss and impairment (e.g. changes in articulation, hearing, eyesight, and swallowing), and sensory changes (e.g. taste and smell) (Fingeret et al., 2012; Henry et al., 2014). Body image concerns are common

among surgically treated HNC patients, often reporting concerns or embarrassment about one or more aspects of their changed body image (Fingeret et al., 2012; Hung et al., 2017). Body image concerns have generally related to changes in functioning, skin discolouration, sensory changes, tooth loss, hair loss, swelling, and scarring. Furthermore, Henry et al. (2014) reported that upon initially seeing their disfigurement, many patients were traumatized and required considerable emotional support. Approximately a third of patients reported social avoidance due to concerns about their appearance, speech, or eating changes (Fingeret et al., 2012). Henry et al. (2014) described an oscillation between ruptured sense of self and normalcy (facilitated by social avoidance), until an eventual acceptance of disfigurement is reached.

1.2.3 Recurrence Fears

Fear of recurrence has been associated with high levels of anxiety and depression in HNC patients, with more than 80% expressing such fears shortly after cancer treatment completion (Humphris et al., 2003). Humphris et al. (2003) explain that these fears remain at consistently high rates throughout follow-up, and several other studies have reported that fear of recurrence is frequently rated as a common area of support need for HNC patients, however these needs are often unmet (Breen et al., 2017; Henry et al., 2014; Rogers, El-Sheikha & Lowe, 2009; Wells et al., 2015). This need also appears to be unmet and problematic across cancer survivors, not just confined to HNC patients (Jimenez et al., 2017).

Although fear of recurrence is a common problem within cancer populations, prevalence rates are inconsistent. Jimenez et al. (2017) reported that 53% of their mixed cancer participants reported recurrence fears, whereas Shay, Carpentier and Vernon (2016) report a figure of 85% for adolescents and young adults (15-39 years), and 79% for older age cancer survivors (40 years and over). However, these studies do consistently report that fear of recurrence is more problematic and prevalent for younger patients experiencing cancer. This may be one explanation for why the fear of recurrence rate for HNC patients has been reported as 35%, which appears substantially lower than the general figures (Ghazali et al., 2013). Jimenez et al. (2017) suggest that recurrence fears were not associated with cancer type within their study, therefore this reduced prevalence in HNC may reflect the later stage in life during which HNC is typically diagnosed and treated. It must also be noted that Ghazali et al. (2013) used a

much smaller sample who were recruited from the care of one consultant, which may have impacted results.

1.2.4 Quality of Life (QoL)

QoL has been described as “the difference, or the gap, at a particular period of time between the hopes and expectations of the individual and that individual's present experiences” (Calman, 1984, p.124). Within this definition, QoL takes into account many aspects of life including present lifestyle, past experience, hopes, dreams and ambitions, and the impact of illness and treatment. The World Health Organisation (WHO, 1995) defines quality of life as “individuals’ perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns”.

Measures of QoL frequently use self-report questionnaires, often split into different domains. The Functional Assessment of Cancer Therapy-General scale (FACT-G; Cella et al., 1993) uses four subscales (emotional, physical, functional and social/family wellbeing) in which 5-point Likert scales are used to rate the patient’s agreement with each statement, ranging from “Not at all” (0) to “Very much” (4). A HNC specific subscale also exists as an addition to FACT-G which includes 12 statements related to common side effects of HNC including difficulties with swallowing, breathing, voice, and pain. The European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-Core 30 (EORTC QLQ-C30) also measures QoL and has a HNC specific subscale scale (EORTC QLQ-H& N37; Björddal et al., 1994), where statements are also rated on a Likert scale.

There is increasing literature regarding the QoL of patients with HNC. Shiraz et al. (2014) noted an inverse correlation between QoL and depression, anxiety, and acute stress. Lower QoL has also been linked to depressive symptoms, fear of recurrence, anxiety, and active and passive coping skills (Dunne et al., 2016). The often adverse effects of HNC on QoL have also been suggested to be a cause of much increased suicide rates in HNC patients compared to the general and other cancer populations (Zeller, 2006). The factors contributing to these increased rates in HNC are under researched, though it is suggested that the impairment of functions often affected by

HNC (e.g. speech, swallowing, and taste) may be particularly difficult to manage and result in suicidal ideation and behaviour (Zeller, 2006).

QoL has generally been reported to deteriorate following commencement of HNC treatment, though may slowly return to the baseline level (time of diagnosis) over time despite the persistence of some functional deficits (Rathod, Livergant, Klein, Witterick, & Ringash, 2015). There is an observed trend of worsening QoL for the initial three to six months after treatment, followed by a degree of recovery (Rathod et al., 2015). However, it is also important to note that a return to baseline QoL is not indicative of good QoL since this may be impaired at baseline as a result of receiving a cancer diagnosis.

It is generally assumed that the functional impairments resulting from HNC treatment translate into poor QoL, however, List and Bilir (2004) have described that there is a subgroup of patients who experience ongoing emotional distress that is not related to functional impairment, though it is unclear what this may instead be related to. Morton (2012) comments on the paradoxical observation that HNC patient sometimes report a higher QoL at one and two years posttreatment than at diagnosis. This has been attributed to a “response shift” which may involve a recalibration of internal standards such that the enduring functional and visible changes are a reasonable compromise in return for cancer-free survival (Breetvelt & van Dam, 1991). However, with longer-term survival (approximately 10 years or more), QoL is lower than at diagnosis, potentially as a result of the dissipated threat of cancer but persistence of symptoms (Morton, 2012).

1.3 Lived Experience of Head and Neck Cancer

General explorations of the lived experience of HNC are documented within the growing HNC literature. Within a metasynthesis of 29 qualitative studies, Lang, France, Williams, Humphris, and Wells (2013) identified six core concepts relating to the experience of HNC. These included: ‘uncertainty and waiting’, ‘disruption to daily life’ (physical functioning financial stability, social life, emotions and family life), ‘diminished self’ (losses associated with sense of self, confidence, self-esteem/image, anticipated healthy future), ‘making sense of the experience’, ‘sharing the burden’ with

emphasis on emotional, practical and informational support from others (friends, family, peers and professionals), and ‘finding a path’ regarding how the individual may see the future – either as ‘different’ or ‘diminished’. Lang et al. (2013) described that patients experienced significant disruption to their daily lives as a result of the emotional and physical effects of HNC and that they made continual efforts to make sense of their experiences in light of their loss of sense of self and future. Supportive relationships were highlighted as particularly important aspects of their experiences, however, this support was sometimes experienced as limited following treatment completion.

Röing, Hirsch, Holmstrom and Schuster (2009) described that new meanings were made for patients following oral cancer, including how they exist as themselves, in the eyes of others, and in relation to others. The authors describe how participants needed to adjust to “a new way of being” in the world, which included realising that a healthy body is often taken for granted and the challenge of living with “invisible disfigurements”, for example a dry mouth. Seeing oneself as ‘normal again’ by engaging in previous activities, and a change towards becoming more thoughtful were also described.

Björklund, Sarvimäki and Berg (2010) explored what it means to live with HNC, and described that patients report it as living ‘in captivity’ as their symptoms serve as constant reminders of their HNC, and their bodily changes rendered them dependent upon others. Feelings of loneliness and isolation in coping with cancer experiences were reported, since the ‘land of the sick people’ is only briefly visited by those who were healthy and well; the HNC patient’s everyday life is perceived as ‘changed forever’. These descriptions matched closely the description provided by Henry et al. (2014), who reported that facially disfigured HNC patients focused on their ruptured self-image as they no longer felt ‘the same person’, with disfigurement also serving as a constant reminder of cancer. Henry et al. (2014) also described an oscillation between ruptured sense of self and normalcy (facilitated by avoidance) until an acceptance of disfigurement was reached. These studies offer valid insights into the lived experience of HNC, however, it must be noted that not all patients who undergo HNC treatments will experience facial disfigurement.

Semple, Dunwoody, Kernchan, McGaugan and Sullivan (2008) reported on the challenges and changes to patients’ lifestyle following HNC and its treatment. The

authors reported on five broad areas in which challenges were faced, including: physical changes, concerns about cancer, interpersonal relationships, social functioning, and work/day-to-day tasks. The authors described that there were many challenges and changes faced within the physical changes, resulting in self-awareness of visible and functional changes, though many were reported to come to an acceptance regarding these challenges, seeing them as the ‘price to be paid’ for survival. Participants were also reported to experience recurrence concerns, major changes in abilities to carry out routine daily tasks, no change or a closer relationship with loved ones, and to engage in self-directed graded exposure to socialising to increase confidence. The authors were careful to explain that these areas of challenge were not discrete or unitary, rather they impacted upon one another. Semple et al. (2008) also reported two themes that concerned attributes that either facilitated or inhibited coping. They found that having a ‘fighting spirit’ and ‘stoic acceptance of cancer’ facilitated patients’ coping with their experiences, and conversely that feeling that changes could not be accepted and having a negative focus inhibited coping.

Lang et al. (2013) provide a good overview of the lived experience of HNC, however, the studies included in the metasynthesis employed mainly descriptive approaches; whilst this is enlightening in areas which are underdeveloped, this area now has a growing research body and requires more in-depth investigation. Furthermore, descriptive studies have the tendency to separate experiences into discrete categories which, whilst conceptually helpful initially, is not representative of the lived reality.

A more recent study has also explored patient’s perceptions of facial disfigurements after HNC surgery (Costa, Nogueira, de Souza Lima, Mendonça, & Leles, 2014). This study reported that patients experienced distress as a result of diminished physical independence, inability to perform routine tasks, and disrupted interpersonal relationships. However, these distresses were often faced with optimism and acceptance of the cancer occurrence. Physical and functional limitations were once again reported as the “price to be paid” for survival, and patients described starting to reconstruct their identity.

1.4 Psychological Service Provision for Head and Neck Cancer

Due to the complexity of HNC, the management of patients' care is often provided by a multidisciplinary team (MDT), which has been described as providing improved outcomes compared to patients managed by a single discipline (Friedland et al., 2011). The professionals comprising the MDT include ENT/head and neck surgeons, oncologists (medical and radiation), radiologists, speech and language therapists and nurse coordinators, though it is recommended that dentists, dieticians, and swallowing physicians are also included (Friedland et al., 2011; Marur & Forastiere, 2008; Nigro et al., 2017). It is recommended that the MDT consider QoL when deciding on treatment goals (Nigro et al., 2017). Murphy et al. (2007b) encourage physicians involved with HNC care to be aware of the psychological as well as physical sequelae of HNC treatment, and to consider mental health as an important component of the MDT approach as it must be addressed to enhance the 'quality of survivorship'.

Several sets of guidelines for the management of psychological aspects of HNC patients have been published (Humphris, 2016; Reich et al., 2014). These include recommendations of routinely screening for psychological distress, specifically focusing on identification of "maladaptive coping strategies", providing an appropriate level of information to patients, and maintaining an open, empathic, reassuring communication style. It is suggested that all clinical staff should routinely assess patients for psychological difficulties, that services should be planned to provide an escalating level of care based on the specific needs dictated by the patients' psychological difficulties, and that there are numerous stages throughout the cancer trajectory when emotional support could be offered. Care may range from 'timely support and educational approaches' to 'complex psychotherapeutic approaches' delivered by psychologists and psychotherapists (Humphris, 2016). These guidelines highlight the need for attention to emotional difficulties to optimise outcomes for patients.

Fingeret et al. (2012) reported that 23% of their HNC patients with body image concerns stated that they would utilize counselling services if they were available to them, though there was a preference for these to be provided within the cancer clinic, rather than from mental health professionals outside the hospital. It was specifically reported that psychological treatment and support regarding body image concerns would be most beneficial to occur prior to commencing cancer treatment to help

patients to develop realistic expectations for body image outcomes. Fingeret et al. (2012) suggested in light of this that CBT or acceptance- or mindfulness-based approaches would suit this population, though there would be a need for them to be tailored to the specific issues of HNC patients.

HNC patients have been reported to receive little support from psychological professionals, with 82% of HNC patients identified with increased level of distress having not received any psychological input (Krebber, Jansen, Cuijpers, Leemans, & Verdonck-de Leeuw, 2016; Singer et al., 2012). These patients are also described to less frequently express a wish for this type of support compared to other cancer groups (Singer et al., 2012). Conversely, Shiraz et al (2014) report that a high proportion of HNC patients they surveyed expressed a willingness to receive psychological input, though few actively sought it. It has been suggested that difficulties relating to emotional distress may be seen as ‘extraneous’ in the face of such life-threatening illness, like HNC, and therefore patients are reluctant to raise these issues with professionals (Lang et al., 2013).

Psychological wellbeing and mental health of HNC patients is an area of growing concern and interest, however, the presence of psychology within a HNC patient’s routine care is still underrepresented. Morton (2012) and Humphris (2008) have highlighted the specific need for psychological input within a HNC MDT as they are well placed to identify means of improving patients’ QoL and survivorship. A Delphi study reported a 100% consensus among health professionals that there is a need for clinical psychology services within HNC care (Breen et al., 2017). This is slowly being realised, with specialist clinical psychology provisions being provided for HNC patients within some NHS Trusts.

1.4.1 Individual Psychological Interventions

The current literature investigating the effectiveness of psychological interventions for HNC patients is sparse and inconclusive. Three systematic literature reviews have been conducted in the area, and although they stated different inclusion criteria, and therefore reviewed mostly different studies, all have reported that it is not possible to come to strong conclusions regarding whether psychological interventions are effective in effecting positive change in psychological distress or QoL for individuals with HNC

(Calver, Tickle, Moghaddam & Biswas, 2018; Luckett, Britton, Clover, & Rankin, 2011; Semple et al., 2013). Some reviews limited their inclusion to randomised and quasi-randomised trials, which although gold standard, restricts the literature possible to review (Luckett et al., 2011; Semple et al., 2013). Nevertheless, even with the exclusion of psychoeducation-only intervention, and less stringent criteria for study design, Calver et al. (2018) still reported insufficient evidence to support conclusions regarding the effectiveness of psychological interventions on QoL. However, they did report that trends towards improvement on emotional wellbeing, physical wellbeing, and functioning wellbeing QoL subscales were observed. These limited conclusions reflect the inconsistent nature of the intervention trials with regard to the trial intervention, outcome measures and follow-up periods utilised, and the scarcity of available literature. It may also be considered that as yet, the processes involved in adjusting to HNC are insufficiently understood, resulting in the interventions not being appropriately targeted.

1.5 Adjustment

1.5.1 Defining Adjustment

In health literature, ‘adjustment’ can be used to refer to the lack of psychological morbidity, and a return to ‘normality’ following a diagnosis or illness. Within HNC literature ‘adjustment’ is commonly commented upon, however, clarification about the authors’ meaning and use of the term is very rarely provided. Furthermore, the operationalisation of adjustment appears to focus on either the presence or absence of psychological morbidities, signifying that adjustment is an end-point of coping, rather than any psychological process of change.

In the development of the Mental Adjustment to Cancer Scale, Watson et al. (1988) defined adjustment as “the cognitive and behavioural responses the patient makes to the diagnosis of cancer” (p. 203). Brennan (2001) criticises this definition on the grounds that it does not place adjustment within a social context, nor does it give any indication regarding what may constitute a healthy or successful adjustment. Hulbert-Williams and Hubbard (2015) use the term adjustment within a cancer setting to mean “the process of change and adaptation that occurs as the individual attempts to integrate cancer into their lives whilst at the same time maintaining some sense of normality and

psychosocial homeostasis” (p. 273). Whilst this definition does not identify the types of changes and adaptations that an individual may engage in, it does acknowledge the process-type nature of adjustment, which is important and missing from other definitions. This study will adopt Hulbert-Williams and Hubbard’s (2015) definition of adjustment.

1.5.2 Measuring Adjustment

Several scales have been developed to assess the psychological responses and adjustment to medical illness, and cancer specifically (Derogatis, 1986; Dunn, Welch, Butow & Coates, 1997; Watson et al., 1988; Watson et al., 1994). Derogatis (1986) developed the Psychological Adjustment to Illness Scale (PAIS), which aimed to assess the psychological and social adjustment to patient illness. This scale existed as a semi-structured interview and as a self-report measure (PAIS-SR), each containing 46 items relating to seven domains. These domains covered areas of: healthcare orientation; vocational, domestic and social environments; sexual relationships; extended family relationships; and psychological distress. Although it was originally designed as a scale for adjustment to general medical illness, it was later validated for cancer patients with comparable factors identified (Merluzzi & Sanchez, 1997). Merluzzi and Sanchez (1997) suggest that as the PAIS-SR provides a broad overview of seven domains associated with adjustment, it is superior to other adjustment scales which may focus on one or two dimensions. However, this broad scope may make the scale more similar to QoL scales, which are comparably broader than the PAIS-SR, therefore leaving the scale in an area of uncertainty regarding its value.

Dunn et al. (1997) developed the Psychological Adjustment in Cancer Scale (PAC) which was developed from an existing adjustment scale for diabetes. The authors reported that whilst the level of distress experienced by cancer patients was greater than that of diabetes patients, it was not qualitatively different. This scale initially included 53 items, however, the refined 21-item scale was demonstrated to have superior psychometric properties. The 21-item PAC related to two factors: impact on daily life, and self-esteem and feelings of helplessness and hopelessness. Dunn et al. (1997) describe that although the measure has demonstrated good psychometric properties, it is limited by relying on self-report of patients, and therefore may be influenced by biased reporting. For example, the PAC cannot identify the use of denial and therefore it is

possible that 'good' adjustment as indicated by PAC scores may simply be a reflection of a patient's denial.

The most commonly used assessment of psychological adjustment is the Mental Adjustment to Cancer Scale (MAC), developed by Watson et al. (1988) and refined to a Mini-MAC by Watson et al. (1994). Both scales are self-report measures and aim to measure the psychological (cognitive and behavioural) responses to a diagnosis of cancer. Watson et al. (1994) describe the Mini-MAC as 'a new measure of adjustment' as it is more efficient and focuses more on cognitive avoidance strategies, though they acknowledge that it is strongly related to the original MAC scale. The MAC and Mini-MAC consist of 40 and 21 items respectively, each rated on a 4-point Likert scale, ranging from (1) 'definitely does not apply to me' to (4) 'definitely applies to me'. Items are arranged into five response categories, including 'fighting spirit', 'anxious preoccupation', 'fatalistic', 'helpless-hopeless', and 'avoidance'. Watson and Homewood (2008) report that responses on the MAC may be generally split into positive and negative adjustments. Greer, Moorey and Watson (1989) validated the original MAC against psychiatrists' assessments of patients' adjustment, concluding that they were satisfactory, however they reported that the scale measures broad categories of coping styles, rather than all psychological responses to cancer and is, as such, limited. Furthermore, there is an inherent difficulty in attempting to 'measure' adjustment as it is a process and these scales are only able to provide a snapshot of how a patient is functioning at one particular time-point. This limitation in being able to measure a *process* of adjustment results in measures of psychological adjustment focusing on specific aspects of adjustment, for example, the types of coping strategies used and psychological distress. Therefore such measures are unable to provide a rich picture of how a patient experiences and progresses through adjustment. However, these types of scales may be a useful starting point to gain a brief insight into how patients perceive they are functioning and their style of coping, as it may provide a target for intervention.

1.5.3 Adjustment in Head and Neck Cancer: Existing Literature

Within the adjustment literature for HNC patients, adjustment is reported as the utilisation of different coping styles and strategies, often reporting on the correlation between coping styles and psychological morbidities (Hassanein, Musgrove &

Bradbury, 2005; Johansson, Ryden & Finizia, 2011; Katz, Irish, Devins, Rodin, & Gullane, 2003; List et al., 2002; Sherman, Simonton, Adams, Vural, & Hanna, 2000). From these studies, successful adjustment is assumed to be the relative absence of QoL issues and/or psychological morbidities. However, none of these studies consider how beneficial coping strategies may be linked together to form a process of adjustment, instead each coping style is reported on as a distinct entity, though it may occur simultaneously with others. This type of reporting on adjustment is also present in the general cancer literature. It has been reported that psychological adjustment is related to types of coping, specifically more positive effects were observed in those participants who used control-type strategies and held beliefs that they had some control over their cancer (Link, Robbins, Mancuso, & Charlson, 2004).

In a correlational study examining the psychosocial impact of HNC, Katz et al. (2003) reported an observed “high level of adjustment” in their HNC participants, citing the low depression rates, positive well-being and high life happiness ratings as the reason for these conclusions. Within this report, the authors did not provide their definition of adjustment and appeared to take QoL and distress measures as an indication of the level of adjustment. Additionally, Eades, Chasen and Bhargava (2009) suggested that progressive weight loss, loss of energy and strength, and decreased physical functioning severely compromise HNC patients’ QoL and health adjustment. They add that the long-term effects of treatments, disfigurement and dysfunction make the three months immediately following treatment, the “most difficult period of adjustment”. Sherman et al. (2000) aimed to identify how coping behaviours may change across different time points of HNC cancer treatment. They reported that generally, patients undergoing or having recently completed treatment had a tendency to use coping strategies such as denial, giving up/withdrawing, focusing solely on the cancer, and emotion ventilation. These types of strategies were found to be related to greater distress, which the authors stated may be indicative of poorer adjustment since coping styles may shape a patient’s psychological adjustment to cancer. However, the authors also suggested that such avoidant-type coping behaviours may be a reflection of the particularly demanding adjustment period that treatment aftermath represents. Vos and de Haes (2007) further suggest that denial and distractive strategies may help to protect against distress and overwhelming difficult feelings.

Using the MAC, Johansson et al. (2011) report that the most commonly used adjustment response within laryngeal cancer survivors was ‘fighting spirit’, which remained stable over a 12-month follow-up period. Helpless-hopeless and anxious preoccupation responses were related to increased anxiety and depression, and decreased health-related QoL. Scharloo et al. (2010) aimed to identify specific cognitions that may be helpful or unhelpful in adjusting to HNC. They reported that negative perceptions regarding the duration and consequences of cancer (e.g. belief that the illness is permanent and self-blame for health-damaging behaviour) predicted lower QoL and therefore poorer adjustment to HNC. It has also been suggested that Acceptance and Commitment Therapy (ACT) may provide a suitable model of adjustment and coping for patients with cancer as it focuses more broadly than on specific psychological morbidities (Hulbert-Williams, Storey & Wilson, 2015).

1.6 Existing Psychological Models of Adjustment

1.6.1 Social-Cognitive Transition Model of Adjustment

Brennan (2001) proposes the Social-Cognitive Transition (SCT) model of adjustment to cancer, which encompasses both personal growth and psychological decline. Brennan views adjustment as a process rather than an end-point. The model postulates an “assumptive world” which contains a representation of ourselves, assumptions and knowledge of how the physical and social world operates. This representation is then used to construct meaning and make predictions, though it is under constant construction and revision. When a novel/unexpected event occurs e.g. diagnosis of cancer, the assumptive world may be temporarily overwhelmed and become unable to react or predict appropriately, as the most fundamental assumptions (e.g. that the world is caring and meaningful, and the self is worthy) are challenged (see Figure 3). The more rigid the assumptive world, the higher the likelihood that psychological distress will occur in response to life changing information. If a prediction is confirmed by experience, the assumption which produced the prediction becomes stronger (this applies to helpful and maladaptive assumptions). Core assumptions that may require adjustment (positive or negative) following a cancer diagnosis are suggested; life trajectory, beliefs of self-worth and control, attachment and spirituality. Whilst these examples may be seen as cancer-specific, the model of adjustment appears not to be. Furthermore, the model was developed from existing theories not direct patient data and

as such may have missed specific aspects that would be specific to developing a cancer-specific adjustment model, for example, dealing with recurrence fears and ongoing functional difficulties resulting from cancer and cancer treatment.

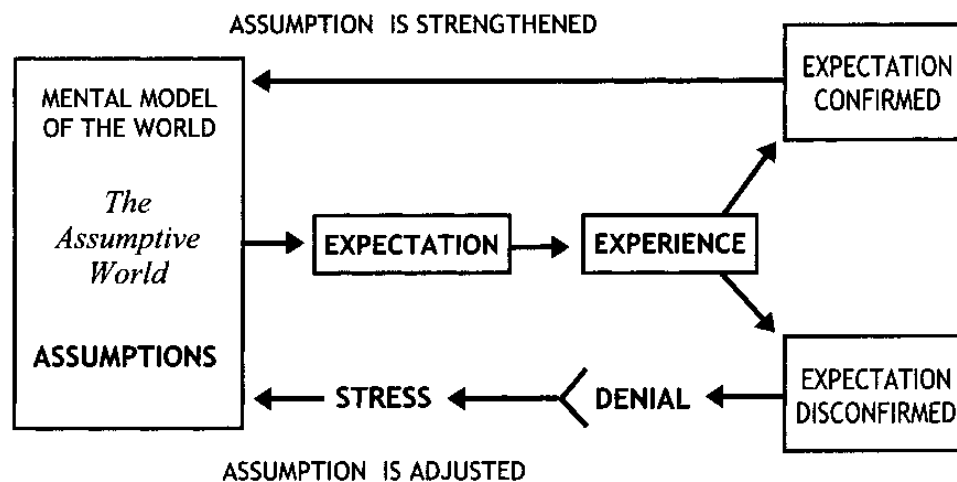


Figure 3. The Social-Cognitive Transition Model of Adjustment (Brennan, 2001).

A further critique of this model is aimed at the individualistic stance that it takes; the social context is emphasised when defining adjustment, however Brennan's (2001) model paid little attention to this and appears heavily cognitive in nature (Hulbert-Williams & Hubbard, 2015). This is a particularly salient issue within HNC as the cancer and its treatment impact largely on individuals' ability to present themselves in a social world and function as a social being (Relic, Mazemda, Arens, Koller, & Glanz, 2001). Hubbard et al. (2013) also express that upon considering adjustment processes, we must include an individual's relational networks – how friends and family adjust to the effects of cancer and its treatment and the impact this has upon their relationships. Due to its cognitive predominance, distress within the SCT model is defined from a medical standpoint; it arises from "faulty thinking" or "unhelpful appraisals" (Hulbert-Williams & Hubbard, 2015). Therefore any intervention based on this model will inevitably seek to change these patterns of thinking styles. However, it is possible that while HNC patients may exhibit negative appraisals, these appraisals are realistic, not exaggerated. The role of emotions within Brennan's (2001) SCT model is also unclear – they appear to be simply a by-product of other processes, however are likely to strongly influence adjustment processes. Furthermore, the model does not explicitly show potential barriers towards experiences being confirmed or disconfirmed.

1.6.2 Model of Restorative Well-Being

Lent (2004) presents two models of subjective well-being. The first describes how, under normative life conditions (i.e. without cancer or other major life events), individuals may maintain their sense of well-being (Figure 4). The second focuses on how individuals may restore well-being and emotional equilibrium when experiencing stressful conditions. Both models are broad and applicable to different life contexts, however, the restorative model has been extended and applied to the cancer coping context (Figure 5; Hoffman, Lent & Raque-Bogdan, 2013; Lent, 2007).

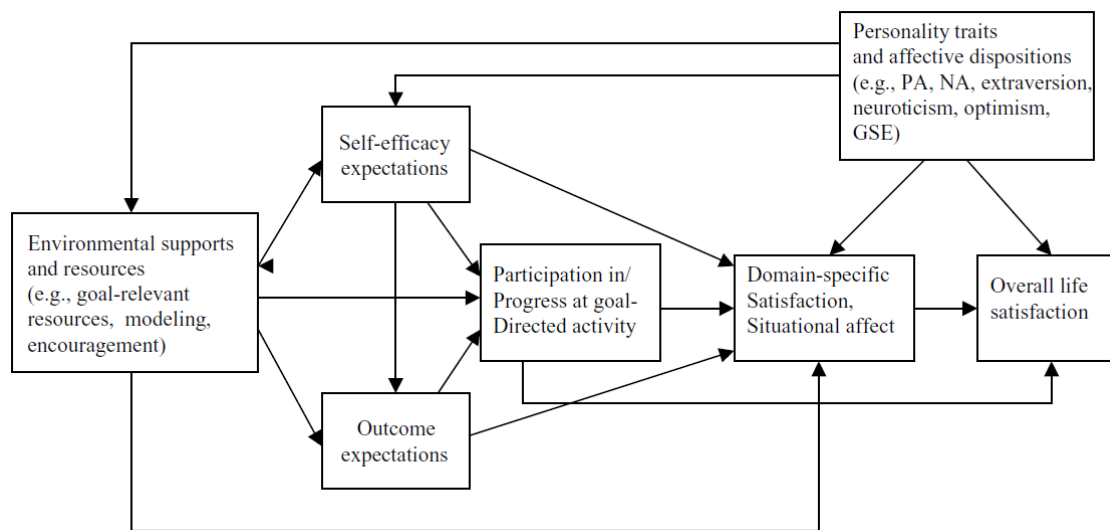


Figure 4. Model of Maintenance of Normal Well-Being (Lent, 2007).

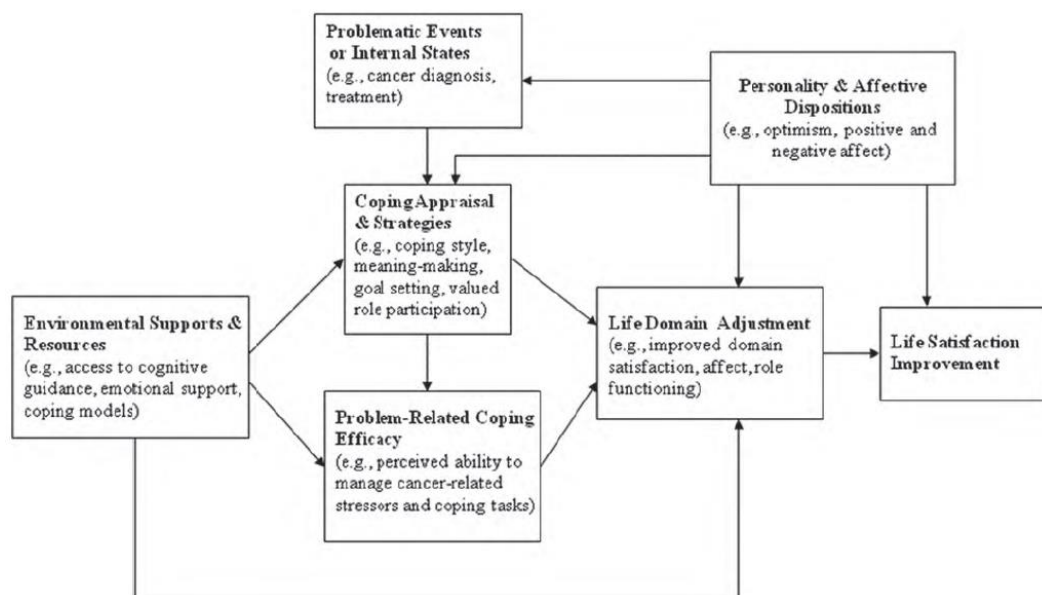


Figure 5. Model of restorative well-being with cancer-specific examples (Hoffman et al., 2013).

The model suggests that the normative process through which individuals maintain their sense of well-being becomes destabilised by an event such as cancer. The restorative model attempts to integrate several factors that have been linked to coping; awareness of a significant stressor, coping strategies, efficacy beliefs, personality factors, and environmental support (Lent, 2004, 2007). Personality traits and affective dispositions are stated to play a central role in life satisfaction as they directly and indirectly affect it through cognitive and behavioural means, however, they do not act alone. The problematic event results in coping processes that involve appraisal of threat and their resources to cope with the threat. Large and unmanageable threats have great adverse effects on life domain satisfaction, though the adverse effects may affect different life domains differently (e.g., work, family, social). Individuals may use different coping strategies (problem-focussed or emotion focussed) to re-establish the emotional equilibrium. Coping efficacy is stated to be an important factor as it partly mediates the effect of coping strategies – coping efficacy allows individuals to make the most of their coping strategies, and to draw effectively on environmental support. Importantly, the model includes the support systems of individuals, and state that they are a crucial part as they have a direct effect on resolving the problem, and indirect effects on supporting coping efficacy (e.g. providing reassurance) and providing sources of coping strategies. The model accounts for professional support within this factor.

Hoffman et al. (2013) assert that whilst the restorative model emphasises strengths and positive adjustment outcomes, it also acknowledges the possibility for lack of recovery and subsequent need for a new baseline, rather than attempting to return to previous levels of functioning. As such, it offers a useful framework for generating research hypotheses and clinical interventions for helping patients cope with cancer. However, they also suggest that applying this model to cancer may be more complex since the problematic event (cancer diagnosis or treatment) may be ongoing, rather than discrete, as with other initial problematic events (e.g. job loss, divorce, bereavement).

1.6.3 A Cognitive Model of Adjustment to Cancer

In line with cognitive theory, the fundamental premise of Moorey and Greer's (2002, 2011) model of adjustment to cancer is that meaning and appraisal play a central role in adjustment to serious illness. They suggest that a diagnosis of cancer threatens fundamental assumptions we hold about our lives; these may be universal or personal

(e.g. that the world is controllable [universal assumption] or that one is a ‘strong’ person [personal assumption]). Moorey and Greer distinguished between the impact of cancer on beliefs about survival and beliefs about who we are. They suggest that the perceived threat to survival may be answered by three questions 1) How great is the threat? 2) What can be done about it? and 3) What is the prognosis? The level of threat may be interpreted in one of three ways: as a challenge, as a major threat (to overwhelm or destroy), or as harm, loss, or defeat. What can be done may be answered by the individual’s perceived level of control over the illness, and the prognosis is an amalgamation of the previous two answers. Adjustment styles identified by Greer and Watson (1987) map onto the answers to these questions, for example, ‘fighting spirit’ may encompass a challenge appraisal of threat and optimism for outcome, helplessness may result from a major threat appraisal and no perception of control, and anxious preoccupation may arise from a major threat appraisal but uncertainty regarding control.

Moorey and Greer (2002, 2011) also suggest that sometimes threat to life is not the most frightening aspect, but the effect of cancer on the patient’s life. Figure 6 shows the negative consequences of a cancer diagnosis, and it is proposed that the appraisal of these threats also shapes patients’ emotional reactions to cancer. Moorey and Greer (2002, 2011) provide an overview of types of information processing, and cognitive biases that may impact how a patient appraises such threats, including all-or-nothing thinking, overgeneralisation, and magnification and minimization, which then become self-perpetuating (Beck, Rush, Shaw & Emery, 1979).

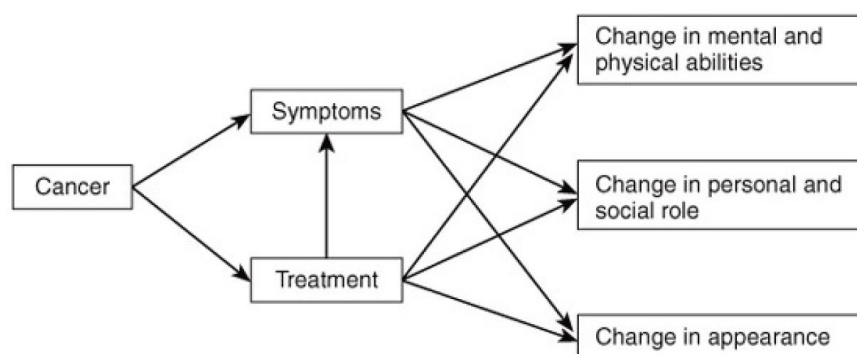


Figure 6. Negative consequences of cancer diagnosis (Moorey & Greer, 2011).

Figure 7 shows Moorey and Greer’s (2002, 2011) model of adjustment, which suggests links between a patient’s meaning assigned to cancer and their emotional and behavioural reactions. Complex relationships are also identified between thoughts,

feelings, behaviours, and physical reactions, though no one component is afforded primacy. The authors also suggest that family and friends play a role in a patient's adjustment to cancer and affect their ability to cope since relationships may change drastically as a result of cancer and its effects. They suggest that family members may have similar reactions and cognitive processes to the patients themselves. The cognitive model also considers the effect of patients' past experiences on their current cancer appraisals, as denoted by the term 'schema' within the model; referring to the pre-established internal structures based on previous experiences.

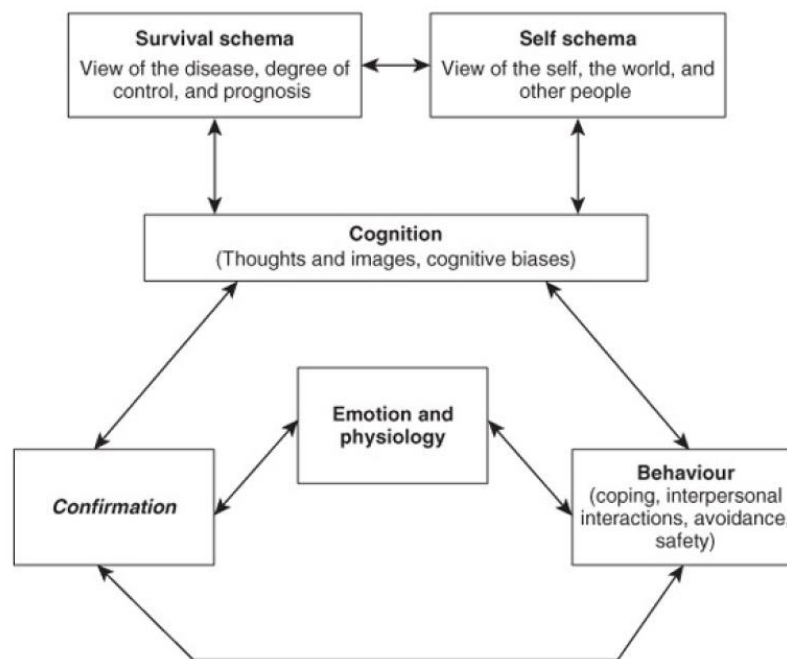


Figure 7. Cognitive model of adjustment to cancer (Moorey & Greer, 2011).

This model's principal focus is on the cognitive appraisal process involved with adjusting to cancer. Various emotional states are discussed within the context of cancer adjustment, however, they feature minimally within the model and are not considered much more than being static and consequential of appraisal outcome. Support for this model arises from the well-documented relationship between coping style and psychological adjustment (de Ridder, Geenen, Kuijer, & van Middendorp, 2008; Hack & Degner, 2004; Johansson et al., 2011; McCabe, McKern & McDonald, 2004), and it offers a clear indication where intervention to assist psychological adjustment to cancer needs to be aimed. Whitaker, Brewin and Watson (2010) demonstrated an effective use of the model in a case study, aimed at reducing psychological distress caused by intrusive memories about cancer. However, its suggestion that adjustment may

predominantly be altered through modifying cognitions may be flawed since the authors explicitly state that the effects of cancer are ‘real’, therefore negative appraisals of the cancer and its effects may be accurate. Interventions based on challenging realistic appraisals may be damaging to patients as they may be experienced as invalidating and disrespectful of their experiences.

1.6.4 Theory of Stress and Coping

Coping is frequently talked about in relation to adjustment, and although the definitions differ slightly, the terms are often used synonymously within the literature. Lazarus and Folkman (1984) define coping as “constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person” (p.141). Johansson et al. (2011) suggest that although the two concepts (adjustment and coping) are often used synonymously within the literature, they do in fact differ in one major way: “the theory of mental adjustment includes emotional reactions to a threatening event, whereas Lazarus and Folkman regard emotional reactions as the outcome of a coping strategy” (p.283). Lazarus and Folkman (1984) consider coping to be a process, rather than a static trait linked to personality, and they categorised them into ‘emotion-focused’ and ‘problem-focused’ forms of coping. These are described as cognitive processes directed towards lessening emotional distress and defining a problem and generating solutions, respectively. The choice of coping may depend on the resources available to the individual, including health and energy, positive beliefs, problem-solving skills, social skills, social support, and material resources. Various constraints may also determine coping strategies available to an individual, including personal constraints (e.g. cultural values and beliefs, or psychological deficits), environmental constraints, and perceived level of threat.

Within meta-analyses of coping literature, coping types have generally been found to map on to Lazarus and Folkman’s (1984) dimensions. Connor-Smith and Flachsbart (2007) distinguished between engagement coping (actively doing something to change the stressor or associated emotion [primary control coping], or to facilitate their adaptation to stress [secondary control coping]) and disengagement coping (acting to distance oneself from their emotions or stressor). Similarly, within breast cancer literature, Kvillemo and Bränström (2014) proposed a hierarchy of coping strategies

which separates different coping styles into categories of coping through engagement or disengagement (see Figure 8). Several authors assert that coping styles are not inherently positive or negative, as coping strategy and outcome should be measured separately, and that different strategies may be functional in different contexts (Connor-Smith & Flachsbart, 2007; Lazarus, 1992). Coping theory and research has been criticised for being of limited practical use to clinicians as a result of it offering limited insight into how coping strategies develop and may result in disrupted relationships (Brennan, 2001). Furthermore, coping theory has been described as focusing on issues that are too broad, and as simply descriptive rather than existing as a formal theory (Salander & Windahl, 1999; Somerfield, Stefanek, Smith, & Padberg, 1999).

HIGHER-ORDER COPING

LOWER-ORDER COPING

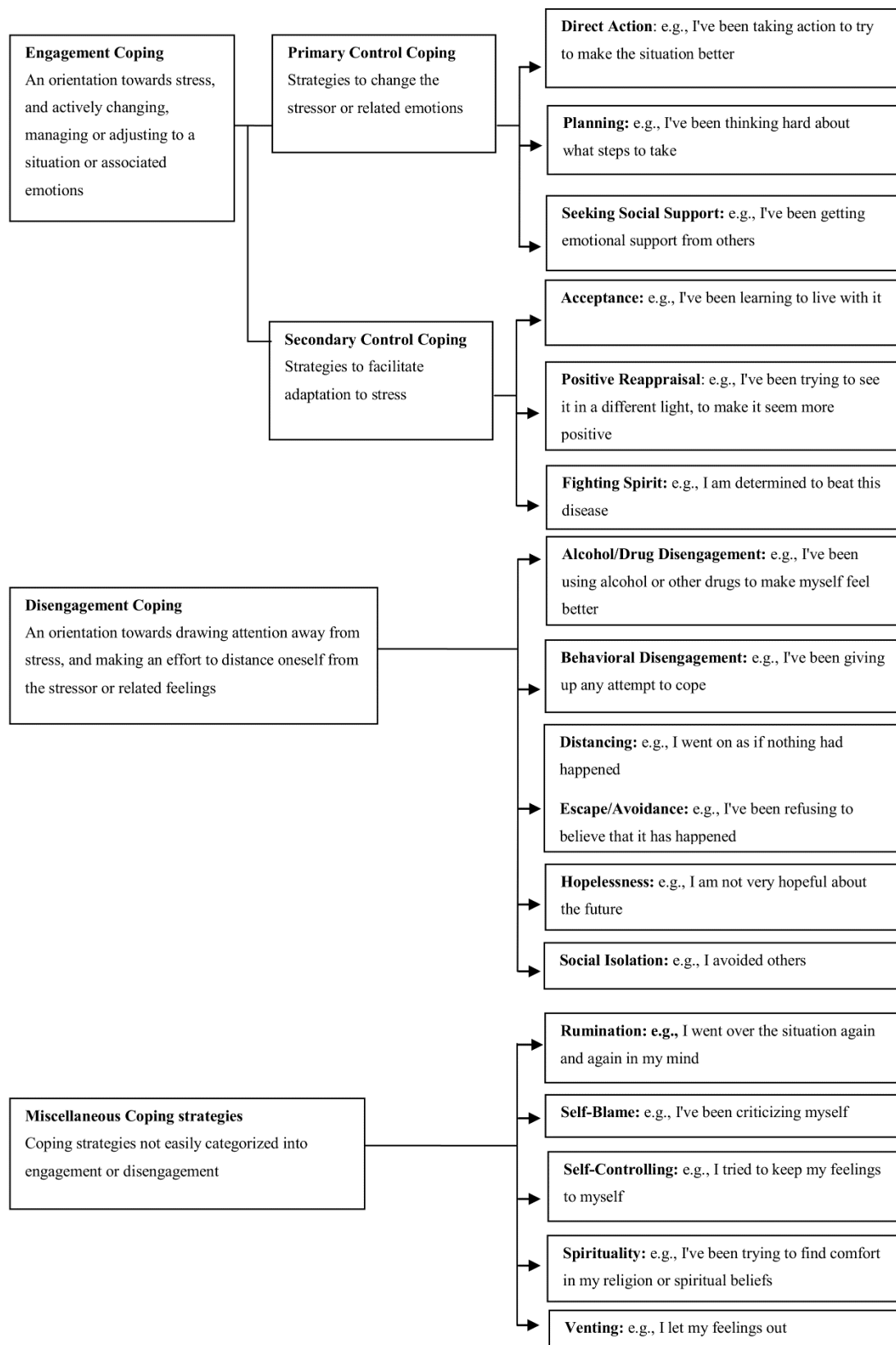


Figure 8. Coping classification hierarchy (Kvillemo & Bränström, 2014).

1.6.5 Transtheoretical Model and Stages of Change

The Transtheoretical Model was developed during research into smoking cessation. Within a comparative analysis of individuals who had stopped smoking independently, and those seeking professional help to stop, DiClemente and Prochaska (1982) identified ten processes of change which were predictive of successful cessation. Further research into this revealed that stages of change were navigated within behaviour change, which led to the development of the Transtheoretical Model (Prochaska & DiClemente, 1983). The model contains six stages which may be exited or re-entered at any time; in proposed order these are pre-contemplation, contemplation, preparation, action, maintenance, and relapse. The processes of change (e.g. consciousness raising, self-reevaluation, and counterconditioning) are used by individuals, and coached by helping professionals, at specific stages to help the individual progress through the stages (Prochaska & DiClemente, 1982; Prochaska, Redding & Evers, 2008).

The Transtheoretical Model has been applied to a wide range of health and mental-health behaviours (Prochaska & Velicer, 1997). Within the cancer literature, it has mostly been applied to cancer screening behaviours in an effort to improve people's attendance to screening procedures (Costanza et al., 2005; Lee-Lin, Nguyen, Pedhiwala, Dieckmann, & Menon, 2016; Spencer, Pagell & Adams, 2005). This model appears to have value in improving behaviours related to cancer, for example, attending screenings, though it may also be a useful framework when considering psychological adjustment processes. Applying the model in this way may help clinicians, or patients, to understand how patients may be supported to start to consider the need for adjustment, and would offer a logical process of how different stages of adjustment may progress.

1.6.6 Theory of Human Motivation

Maslow (1943, 1970) proposed a model of human motivation in which he asserted that all individuals are motivated to achieve and satisfy certain needs. He stated that an individual is dominated by, and its behaviour is driven by, its unsatisfied needs. Furthermore, Maslow suggests that most behaviour is multi-motivated. Needs are arranged hierarchically from basic, deficiency needs to growth needs, and once a need is

met (however partially) another ‘higher’ need emerges. Basic, deficiency needs arise due to a deprivation in these and motivate individuals until they are met. Growth needs, however, stem from a desire to grow as a person, rather than from a lack of something. The first deficiency need is posited to be physiological needs followed by safety needs, belonging and love needs, and esteem needs. Growth needs start with cognitive needs, followed by aesthetic needs, self-actualisation, and finally transcendence.

Maslow asserts that each individual is capable and motivated to move up the hierarchy, though this progress may be disrupted by failure to meet lower needs, or by life experiences. It is possible for individuals to move back and forth between levels. Within his discussion on ‘safety needs’, Maslow (1943) suggests that an experience of illness may produce needs that have not previously been observed in an individual, for example searching for a protector or stronger person to depend on. Due to the disruptive effects of cancer, it is clear that Maslow’s theory would be applicable within this context, however, there is a paucity of literature in this area. Maslow’s theory has been applied within palliative care settings, as an alternative to the medical model, to guide the care-planning and care provision of patients in the end stages of life (Herbst, 2006; Zalenski & Raspa, 2006). The authors report that use of the model improves the completeness of care as it encourages growth needs to be met rather than just basic needs, like symptom management. Maslow’s (1943) original five-stage hierarchy of needs has been applied to the breast cancer setting in studies attempting to map breast cancer patients’ needs throughout the cancer trajectory (see Figure 9; Ng, Ong, Jegadeesan, Deng, & Yap, 2017; Schmid-Buchi, Halfens, Dassen, & van den Borne, 2008). Ng et al. (2017) suggest that in a breast cancer setting, all needs are assessed and managed concurrently and they identify the composition of needs at different stages within the cancer treatment journey, illustrating how Maslow’s theory may be used to help healthcare professionals to meet these needs. Whilst Maslow’s theory is compelling and appears robust in its application to cancer, it currently remains under-used and under-considered as a helpful framework to guide holistic care. At present, it has not been applied to the process of adjusting to cancer.

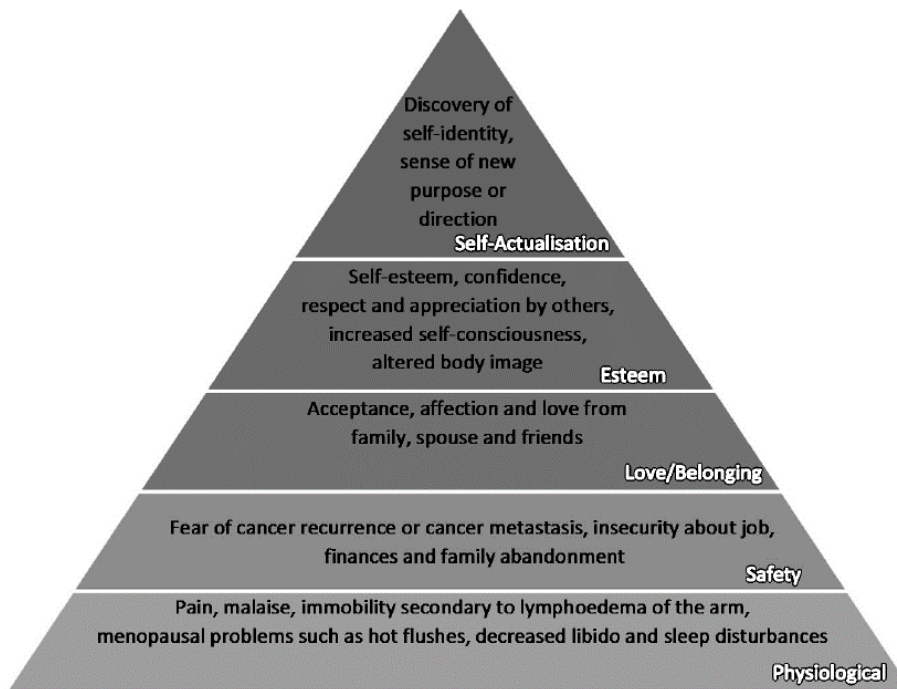


Figure 9. Maslow's hierarchy of needs applied to cancer (Ng et al., 2017).

Chapter 2. Methodology

2 Extended Methodology

2.1 Study Rationale

2.1.1 Research Paradigms

A paradigm is a “basic belief system or worldview that guides the investigator”, defining what constitutes legitimate inquiry (Guba & Lincoln, 1994, p. 105). A research paradigm is built from, and interconnected with, the responses to ontological, epistemological and methodological questions. Ontology refers to the nature and form of reality and what can be known about it. Epistemology refers to the relationship between the researcher and the knowledge of reality, and methodology refers to methods utilised to find out what may be known (Guba & Lincoln, 1994).

Four paradigms were described by Guba and Lincoln (1994): positivism, post-positivism, critical theory, and constructivism. Traditionally, scientific inquiry and research has employed, and valued, a positivist paradigm; that there is an objective and measurable reality from which causal relationships may be identified (Henwood & Pidgeon, 1995). More recently, ‘scientific method’ epistemological positions are described as positivist-empiricist or hypothetico-deductive; both adopt a realism ontological assumption (that there is an objective, observable reality), though they differ regarding the extent to which they state that theoretical assumptions can be definitively verified (Coyle, 2015). Within social science some authors have expressed dissatisfaction with the ‘scientific’ paradigms, especially within health psychology, since process, context, and strategies for new theory generation are often neglected in favour of hypothesis testing and theory verification (Henwood & Pidgeon, 1995; Murray & Chamberlain, 1999). Alternative epistemological positions such as critical realism and social constructionism allow an individual’s experiences and context to be considered, which ultimately determines how reality may be observed or constructed through language (Coyle, 2015). Pidgeon and Henwood (1997) advocate for human and social sciences to consider the meaning and understanding an individual assigns to a phenomenon within its inquiry paradigm. Therefore, the present study seeks to gain an understanding, from a patient’s perspective, of the psychological process that they go through when adjusting to HNC.

2.1.2 Rationale for Qualitative Methodology

This study aimed to inductively investigate personal accounts of HNC experiences to generate an understanding of the process through which individual's journey when adjusting to such an event. It is argued that through qualitative research methods, we may start to understand the "construction of health and illness" as they preserve the depth and richness of an individuals' account (Mathieson, 1999; Murray & Chamberlain, 1999). Qualitative research may be seen to play an essential role in developing psychological knowledge and understanding, and is considered a legitimate field of inquiry, rather than as a precursor to subsequent quantitative research (Denzin & Lincoln, 2011; Henwood & Pidgeon, 1992).

Qualitative research is concerned with developing a rich understanding of how meaning and experience are constructed, rather than testing and confirming abstract, universal theories (Henwood & Pidgeon, 1995; Pidgeon & Henwood, 1997). Qualitative researchers work with data within the constraints of the social world, rather than trying to abstract the data from it, as quantitative methods do. This is particularly useful in the present study, since the personal circumstances in which HNC occurs, and the idiosyncratic impact that this has on the individual and those around them, are likely to be important factors in the adjustment process (Denzin & Lincoln, 2011). Psychological adjustment to an experience is a process – qualitative data provide rich descriptions of processes, and qualitative analysis is an effective way of studying processes as it allows the researcher to look beyond their initial pre-conceptions and generate new understandings (Miles & Huberman, 1994).

In areas where existing knowledge is limited, qualitative research provides an effective strategy for exploration and hypothesis development (Miles & Huberman, 1994). Inductive qualitative research allows for the emergence of complex concepts and relationships that could not have been anticipated in advance. As these would not have been anticipated, it is unlikely they would be captured using predetermined response categories, or other quantitative measures (McEvoy & Richards, 2006). Due to the features described above, a qualitative paradigm was considered to be the most appropriate to meet the aims of this study; to develop an understanding and theory regarding the process of how individuals adjust to the experience of HNC.

2.1.3 Epistemological Position

Within research paradigms, critical realism is located as a middle ground between positivism and constructivism, drawing from both regarding its epistemology and ontology (Denzin & Lincoln, 2011). Critical realism states that an external world exists, independent from human experience, though our perception of this world is incomplete and is dependent upon our beliefs and expectations (Bunge, 1993; Danermark, 2002; Denzin & Lincoln, 2011). Since only parts of reality are accessible, and our knowledge is socially constructed, critical realists accept that any theory developed will not be a true representation of reality (Guba & Lincoln, 1994; Wimpenny & Gass, 2000). However, within a critical realist position, the ultimate goal is not to establish generalizable theories, or document lived experiences, but to develop deep understanding and explanation of social processes (McEvoy & Richards, 2006; Miles & Huberman, 1994).

Critical realism engages in explanation and acknowledges that reality extends beyond what can be empirically known; these qualities make it particularly useful for analysing social phenomena (Fletcher, 2017). Within critical realism, reality is stratified into three domains: empirical (what may be experienced and observed); actual (events occur even if they are not observed); and real (causal mechanisms that produce the events) (Bhaskar, 1978; Fletcher, 2017). Although not available for direct observation, it is the aim of critical realism to explain social events via inferences drawn about these causal mechanisms and the effects they have within the different domains gathered through scientific investigation and theory generation (Fletcher, 2017; McEvoy & Richards, 2006).

Murray and Chamberlain (1999) suggest that within health psychology, a relationship exists between the physicality of illness and the individuals' narratives regarding the meaning they have created about it. A social constructionist approach would neglect the physicality of the cancer experience, and a positivist approach would deny the importance of the individuals' constructed meaning. Instead, a critical realist epistemological position fits the present study well; investigation into the psychological adjustment to HNC. Cancer (and its effects) is an experienced event that undoubtedly occurs, however, adjustment to this experience is subject to an individual's meaning and understanding of this event.

2.2 Grounded Theory

Glaser and Strauss (1967) originally presented grounded theory methodology as a means of “closing the embarrassing gap between theory and empirical research” (p. vii). Unimpressed by the positivist paradigm for social research, and theories developed from a “logical deduction of a priori assumptions” (Glaser & Strauss, 1967, p. 3), Glaser and Strauss offered grounded theory as a general methodology for generating a theory grounded in data that has been systematically gathered and analysed (Strauss & Corbin, 1994). Grounded theory places emphasis on theory development; deriving theories inductively from the data through a research process of simultaneous data collection and analysis (Glaser & Strauss, 1967; Strauss & Corbin, 1994). A key feature of grounded theory is the ‘constant comparative analysis’ which is used throughout the theory generation process (Glaser & Strauss, 1967). This also aids in the verification of hypotheses throughout the research process, rather than relying upon follow-up quantitative research (Strauss & Corbin, 1994).

Despite their original collaborative work in developing grounded theory methodology, Glaser and Strauss reached a point at which their opinions regarding the aims, principles, and procedures associated with grounded theory were too divergent to be considered one methodological approach (Goulding, 1999). These fractures between the original authors led to two distinct, and competing, modified approaches to grounded theory methodology – each informed by different ontological assumptions (Goulding, 1999; Hunter, Murphy, Grealish, Casey & Keady, 2011). Straussarian grounded theory offers systematic guidelines and coding techniques to make the methodology more transparent to researchers (Strauss & Corbin, 1990, Corbin & Strauss, 2015; Hunter et al., 2011), and constructivist grounded theory seeks to build a mutual understanding of researched phenomena through collaboration between researcher and participant (Charmaz, 2006, 2014; Hunter et al., 2011).

2.2.1 Rationale for Grounded Theory

Grounded theory is unique in its intention to generate an explanatory theory, rather than to produce an in-depth description of lived experiences. A ‘grounded theory’ aims to provide an understanding of a phenomenon and the processes involved (Corbin & Strauss, 2015; Strauss & Corbin, 1990). Within health psychology, research is often limited to outcomes, however, other issues within health psychology often involve

processes, for example: recovery; adjusting to a chronic illness; and dealing with intrusive medical procedures (Chamberlain, 1999). Grounded theory has been suggested to be particularly useful when investigating situations to which people must adapt as the theories generated are often complex rather than oversimplified (Corbin & Strauss, 2015; Turner, 1981). The complexity of the theory afforded by grounded theory methodology adds to the utility of the theory since the theoretical explanation offered closely fits the situation investigated, and therefore makes it more usable (Turner, 1981). Since adjustment to HNC is a complex process, the generation of a theory to explain this process would answer the research question of ‘how do patients adjust psychologically to the experience of head and neck cancer’.

Cutcliffe (2000) suggests that to ensure integrity of the study, one method of grounded theory must be chosen and adhered to, with any deviations explained. The selection of the method must be aligned with the epistemological position of the researcher (Annells, 1996). Therefore, I chose to use Corbin and Strauss’ (2015) framework for grounded theory as this fits with my critical realist stance. Oliver (2012) suggests that grounded theory is particularly compatible with a critical realist approach as together, they provide a methodology that is accessible and ties research firmly to practice. The formal guidance and structure to approach potentially bewildering qualitative data, offered by Corbin and Strauss (2015) is also particularly attractive to new researchers (Henwood & Pidgeon, 2003; Rennie, 1998). These explicit techniques and procedures are described as “both reassuring and genuinely useful” (Henwood & Pidgeon, 2003, p. 133).

2.2.2 Critique of Grounded Theory

Grounded theory is not without criticism; it is particularly critiqued regarding some of its terminology, for example, that the theory ‘emerges’ from the data and is ‘discovered’. It is argued that terms such as ‘discovery’ and ‘emerge’ downplay and neglect the creative and interpretive role of the researcher within grounded theory analysis and theory generation (Henwood & Pidgeon, 1992, 1995; Willig, 2013). Furthermore, since grounded theory works inductively, it assumes that the data ‘speaks for itself’, and therefore reflexivity and the role of the researcher are insufficiently attended to (Willig, 2013). However, Pidgeon and Henwood (1997) argue that reflexivity is important within grounded theory, and recommend that the researcher

documents each stage of the process. This increases the reflectivity of the research and facilitates the researcher to be explicit about their own assumptions, values, and interpretations.

Willig (2013) suggests that Corbin and Strauss' (2008) provision of a step-by-step guide introduces a deductive element to grounded theory, making it prescriptive by sensitising the researcher to particular aspects such as 'process' and 'change'. This is argued to undermine the purpose of open coding, which allows the data to speak for itself. Despite this step-by-step guide, Pidgeon and Henwood (1997) claim that a major flaw in grounded theory methodology is that the critical step between data components and generating a full explanatory theory is not well defined or explained. Moreover, it is unclear whether the methods used within grounded theory are distinctive to this particular qualitative approach to analysis (Henwood & Pidgeon, 2003).

Nevertheless, grounded theory offers a qualitative approach which addresses both realism and relativism (Rennie, 2000). Grounded theory acknowledges that the theory generated will be relative to the researcher producing it, however, this is acceptable as long as the theory remains grounded within the data. Grounded theory's inductive nature also allows it to be self-correcting, which allows the generated theory to be accepted as sufficient scientific inquiry, rather than just being the first step and requiring subsequent verification (Rennie, 2000). Although qualitative research is becoming more universally accepted, the verification process, embedded into grounded theory methodology (constant comparison), allows the generated theory to be accepted within a research climate dominated by the positivist position (Charmaz, 2014; Rennie, 1998; Strauss & Corbin, 1990).

2.3 Alternative Qualitative Approaches

Three alternative qualitative data analysis methods were also considered for this study. These are briefly outlined below with reasons why they were less appropriate than grounded theory for the current study.

2.3.1 Discourse Analysis

Discourse analysis is concerned with how reality is constructed through the subtle use of language and is situated within a constructionist epistemological position (Potter, 1996; Potter & Wetherell, 1987). Discourse analysis rejects the notion that individuals' speech or writings may be analysed to uncover the underlying psychological processes that have produced it (e.g. cognitive distortion), and instead focuses on language as a form of social action (Potter, 1996, 2012; Potter & Wetherell, 1995). Thus, discourse analysis aims to develop an understanding of what an individual is 'doing' by using particular language (Potter, 2012). Investigation into how participants use language to construct their adjustments to head and neck cancer would be an interesting and valid topic, however, this is not the aim of the current study, and a constructionist approach is inconsistent with my critical realist position. This study aims to generate a theory regarding the process of adjustment to HNC, which will likely involve reference to psychological processes, therefore discourse analysis is not an appropriate approach for this study.

2.3.2 Interpretative phenomenological analysis (IPA)

IPA aims to examine and explore, in detail, how participants perceive and make sense of major life experiences (Smith, Flowers & Larkin, 2009). IPA acknowledges that the personal world of participants is not directly or completely accessible to the researcher, and as such is subject to double hermeneutics (Smith et al., 2009). This refers to the situation in which the researcher must interpret a participant's account of events to understand their experience, however, the participant's account is also their own interpretation of events and experiences (Smith, 1996; Smith et al., 2009). In this respect, IPA is concerned with the participant's personal account of the life event, rather than attempting to obtain an objective statement about the event (Smith, 1996; Smith & Osborn, 2015). Due to its focus on major life events, IPA may contribute particularly to health psychology (Smith, 1996), and would form an interesting study into the meaning of HNC experiences. IPA is compatible with a critical realist position, and how participants make sense of their HNC experience may be a factor in their adjustment. However, IPA is not aimed at developing an explanatory substantive theory which advances beyond the level of experience, which is the aim of the present study.

2.3.3 Thematic Analysis

Thematic analysis presents a method for identifying, analysing, and reporting patterns of meaning (themes) in relation to a particular research topic (Braun & Clarke, 2006, 2012). Braun and Clarke (2006, 2012) acknowledge the debate regarding whether thematic analysis is a distinctive method for qualitative data analysis, since it is comprised of components that are common to many qualitative approaches (Ryan & Bernard, 2000). However, they argue that thematic analysis is a distinct and flexible method which is compatible with several epistemological positions, and set out guidelines for conducting thematic analysis (Braun & Clarke, 2006). Thematic analysis is described as a method, not a methodology since it comprises of theoretically independent qualitative analysis tools, rather than being bound by theoretical assumptions and frameworks (Clarke, Braun & Hayfield, 2015). It has the flexibility to be used at a descriptive, semantic level, or at a more sophisticated, interpretive level (Braun & Clarke, 2006; Clarke et al., 2015). Although thematic analysis is flexible, compatible with a critical realist position, and has many similarities with grounded theory regarding steps in analysis, the focus remains on identifying and making sense of themes across a data set. The aim of this study is to interpret and integrate these themes further into a substantive theory. Grounded theory methodology offers a framework in which to achieve the aims of the current study, and has the benefit of using an iterative process of revising interview questions to develop and refine theory, even extending to sharing the theory with participants to gain further data (Corbin & Strauss, 2015). Whilst these beneficial aspects would be possible to complete within a thematic analysis study, they are not inherent in the methodology; thematic analysis generally seeks to look across an entire dataset.

2.4 Sampling and Participants

2.4.1 Theoretical Saturation and Sufficiency

Corbin and Strauss (2015) advocate that data collection and analysis should continue until theoretical saturation is achieved. Theoretical saturation refers to the point at which no new concepts emerge from the data. Corbin and Strauss (2015) emphasise that theoretical saturation encompasses more than simply the lack of new categories emerging from the data – the existing categories are well-developed, including how concepts relate to one another and the core category, and how they may vary under

different conditions. However, theoretical saturation may not always be possible, especially in small-scale studies (Pidgeon & Henwood, 1997). Furthermore, complete theoretical saturation within grounded theory may be unattainable since interview questions are refined and developed in line with the data and as such can always be directed towards discovering exceptions and new concepts. Dey (1999) suggests a more practical concept of theoretical sufficiency, in which categories may adequately cope with additional data without requiring continual modification. Within the current study, theoretical sufficiency was considered to be the point at which the data provided adequate concepts and depth to develop a theory which covered the topic sufficiently, without 'gaps' in the theory.

2.4.2 Sample Size

Due to the focus on theoretical sampling within grounded theory studies (Glaser & Strauss, 1967), determining the sample size required for a grounded theory study differs from other methodologies. Theoretical sampling is driven by the emerging theory in which concepts and categories are sampled, rather than individual people (Corbin & Strauss, 2015). In order to achieve theoretical sufficiency (Dey, 1999), the sample size would be determined by the point at which the categories and concepts explored within the study are not enhanced by further data collection and analysis (Strauss & Corbin, 1990; Corbin & Strauss, 2015). Nevertheless, interviewing additional participants could always give rise to new information, especially if they have key characteristics that are different to the other included participants in ways which are relevant to the research question. Within the published literature there is wide variation in sample sizes for grounded theory studies, with examples ranging from seven to 245 participants (Adamson & Braham, 2011; Mottram, 2011). However, Crouch and McKenzie (2006) suggest that qualitative methodologies, such as grounded theory, are very labour-intensive and small sample sizes are therefore justified. Owing to the richness of information gathered within interviews, and the depth of meaning to be achieved, small sample sizes are preferable since intensive analysis is much more persuasive than extensive sampling that aims to be convincing through enumeration (Crouch & McKenzie, 2006).

Based upon previous studies into the exploration of HNC (see Lang et al., 2013 for a review) and the time available for this research, I anticipated that approximately 10-15

participants would be required for this study. However, other published grounded theory studies have used as few as nine participants within the field of HNC (Griffiths, Humphris, Skirrow & Rogers, 2008; Jakobsson, Horvath & Ahlberga, 2005).

2.4.3 Eligibility Criteria

Participants were invited to interview following their expression of interest in the study if they met the inclusion criteria (detailed in the Journal paper). It was also considered that participants may be excluded if they were unable to communicate verbally, but only if their level of written English was not sufficient for the interview process. Special requirements for individuals who struggled to speak for an hour was considered e.g. multiple shorter interviews, however these were not required for the recruited participants.

It was decided that there would be no exclusion criteria based on whether participants had received treatment for their cancer, or psychological support directly relating to their cancer. This was because adjustment is a dynamic process and the present study aimed to incorporate the adjustment to a spectrum of experiences of HNC.

2.4.4 Participant Recruitment

Purposive sampling was used to identify and recruit participants who had experience of HNC so that data collected within interviews would be detailed and relevant to the study question. After gaining the necessary ethical approvals (see section 2.5), the first author (LC) emailed clinicians who had agreed to approach and recruit participants for the study; informing them that the study was in a position to commence recruitment (see Appendix 2 for an example). Recruiting clinicians were provided with a letter detailing the aims and eligibility criteria of the study (Appendix 3), participant information sheets (Appendix 4), and contact details forms (Appendix 5).

Participants were recruited from four general hospitals across two counties in the East Midlands, and were initially approached by a member of their usual care team (clinicians who had agreed to recruit for the study; a psychologist, two oncologists, and a consultant maxillofacial surgeon). Potential participants were informed about the study and provided with a participant information sheet. It was explained to potential participants that entry into the study was entirely voluntary and that their treatment and

care would not be affected by their decision. Upon expressing interest in participating in the study, potential participants were encouraged to make contact with the researcher via contact details provided on the participant information sheet. If participants preferred the researcher to make initial contact, they were provided with a contact details form to complete, detailing their preferred form of contact.

During initial contact with participants, they were given the opportunity to ask questions about the study and their participation. Eligibility for inclusion in the study was also reviewed before a convenient time and place for the interview was arranged.

2.4.5 Participant Withdrawal

Participants were advised that they may withdraw from the study at their own request at any time during the interview, and up to seven days following completion of the interview. It was also made clear that their decision to withdraw would not affect any future care. This information was available to the participants via the information sheet, consent form, debrief sheet (Appendices 4, 6, 7), and was discussed at the initial meeting and after the interview. Participants were also made aware that should they withdraw, the data collected to date could not be erased if the withdrawal request was received more than seven days after their interview and as such may still be used in the final analysis. No participants requested to withdraw from the study.

2.5 Ethical Considerations

Approval for the study was sought from the University of Nottingham sponsor. Following this approval, ethical approval was sought and was granted by the East Midlands NHS Research Ethics Committee. Health Research Authority approval was also gained, along with capacity and capability confirmation from each of the NHS Trusts Research and Development departments from which participants were recruited (Appendix 8). A Letter of Access for the first author (LC) was also gained for each research site to recruit participants and conduct interviews at these sites. In applying for the Letters of Access, an e-learning module for 'Introduction to Good Clinical Practice' was also completed and certification gained (Appendix 9).

Written informed consent was gained from each participant before each interview commenced. Prior to this, the details of the study were explained to the participant and an opportunity given to ask any further questions. The occurrence of an adverse event as a result of participation within this study was not expected and therefore, no adverse event data was collected.

Due to the personal nature of the experience discussed within interviews, it was anticipated to potentially evoke difficult emotions; participants were supported as necessary including signposting to additional avenues of support if appropriate. These included advice to contact their GP, the Samaritans, and a weblink to resources provided by Kingsmill Hospital Macmillan Clinical Psychology (this information was also provided within the debrief sheet). It was also expected that since the researcher conducting the interviews (first author; LC) was a Trainee Clinical Psychologist they would be able to contain any distress within the interview. Nevertheless, participants were informed through the consent form that they reserve the right not to answer a question without reason and may withdraw from interview at any time. Participants were also debriefed at the end of the interview, offered the opportunity to ask questions or voice concerns, and were provided with a debrief sheet which contained contact details for the first author (LC) in the event that they had any further questions or concerns (Appendix 7).

Each participant was assigned a pseudonym, against which their data was stored to ensure confidentiality. This data included participants' demographic information, other study documents and the anonymised transcription of their interview. Within the transcription process, all additional identifying information was removed, e.g. names of individuals/places. Transcription was provided by a professional service following the signing of a confidentiality agreement between the transcriber and researcher (Appendix 10). The use of an external transcriber was made clear to participants within the participant information sheet and consent form. This study was conducted in accordance with the Data Protection Act (1998). The minimum required information was collected, and all participant data was stored in a locked filing cabinet at the University of Nottingham. Data was only made accessible to the researcher, research supervisors, and the transcriber. Interview data (audio-recordings and transcripts) were stored electronically on an encrypted data stick, and were password protected.

2.6 Data Collection

2.6.1 Interviews

Grounded theory studies may use the same forms of data as other qualitative methodologies, including text, interview, observation, or focus groups (Corbin & Strauss, 1990; Goulding, 1999). It is important that the form of data collection is appropriate for the research question and methodology (Wimpenny & Gass, 2000). Data for this study was collected through individual interviews as this permitted in-depth discussion and exploration of participants' experiences of adjusting to HNC, thus producing rich data for analysis. Mathieson (1999) suggests that interviews may be a particularly powerful tool when studying the experiences of individuals with illness. The aim of the interviews was to explore adjustments made by participants following experiences of HNC, and possibly treatment (though it was not stipulated that participants must have received treatment for inclusion within the study). It was considered that participants' experiences may be of a sensitive nature and therefore individual interviews were preferable to focus groups.

Interviewing provides a good fit for grounded theory methodology since it allows the researcher to initially approach data collection with a broad overview of topics to be explored, and topics explored may be revised and become more focused as data collection and analysis proceeds (Wimpenny & Gass, 2000). Within a grounded theory methodology, researchers may begin data collection with either unstructured or semi-structured interviews (Corbin & Strauss, 2015). Unstructured interviews offer participants an opportunity to talk freely about issues pertinent to them (given the topic of research), and placed control of the interview with participants. However, conducting unstructured interviews has its challenges, especially for novice researchers, since it requires skills of facilitating the flow of information which can be difficult to establish when the researcher is nervous, or the participant is not particularly talkative (Corbin & Strauss, 2015). Furthermore, participants often request guidance regarding what information is being sought from them, and a completely unstructured interview has the potential to yield confusing and meaningless data (Goulding, 1999). A balance must be found between offering guidance on the topics of interest, enabling the participant to feel comfortable enough to also add topics pertinent to them, and imposing the researcher's biases and assumptions upon the interview, thereby impeding any new insights and simply reflecting the researcher's expectations (Goulding, 1999). By using

semi-structured interviews, participants were encouraged to explore issues relevant to them, whilst remaining focused on considering their adjustment to HNC. General themes and topics for exploration were developed prior to the interviews for the first author (LC) to remain focused on the research aims within the interviews, however, how and when these topics were presented was not pre-defined or structured. Participants were also encouraged to add topics they thought were important even though they may not have been directly asked about. Using semi-structured interviews helped the interviews to remain focused on the research aims, but also provided the flexibility required for developing theory and new insights (Corbin & Strauss, 2015).

Interviews were conducted either face-to-face (at a hospital site or in the participants' homes) or via telephone. Face-to-face interviews have generally been considered to be the gold standard as they provide additional contextual and nonverbal cues, such as body language (Novick, 2008; Rahman, 2015). Nevertheless, face-to-face interviews can be costly regarding time and travel expenses and the additional social cues afforded by them may not be of particular interest to researchers, depending on the research topic (Opdenakker, 2006). Telephone interviews have generally been opposed since they have reduced access to social cues and have been considered to yield lower quality data. However, these claims are often unsupported as telephone interviews have been demonstrated to produce high-quality, rich data (Novick, 2008). Furthermore, it has been claimed that the anonymity afforded by telephone interviews may allow participants to disclose sensitive information that they may not have provided in face-to-face interviews (Novick, 2008; Opdenakker, 2006). It was considered that social cues such as body language were not of specific interest within this study and therefore telephone interviews may provide greater opportunity to recruit participants since they may be more convenient for potential participants. However, I also offered participants the choice of having a face-to-face interview conducted at their own home since many participants have the potential to have communication difficulties, for example struggling to project their voice, and as such telephone interviews may be challenging for them.

Before each interview commenced, participants were reminded of the research aims and that the interview would be audio-recorded for later transcription. Participants were also

advised that they could chose to withdraw and terminate the interview at any time, without giving a reason (see sections 2.4.5 & 2.5).

2.6.2 Interview Schedule

The general themes of the interview were developed from the aims of the project and consultation from experts in the field (two Oncologists and a Macmillan Clinical Psychologist [fourth author; SB]). I also attended a head and neck MDT meeting and a head and neck oncology outpatient clinic to inform the initial development stages of the interview schedule. The interview questions aimed to be open-ended so that new theoretical insights may be gained, rather than closed-questions which would only serve to test pre-defined ideas (Corbin & Strauss, 2015). The questions covered five broad areas related to adjustment to HNC and were designed to allow participants to explore and freely discuss their experiences in adjusting to HNC. Questions were carefully worded to not be leading, and to encourage participants to expand upon, and add, topics that they felt were important in their adjustment process.

The broad areas initially explored included: participants' understanding of the term 'adjustment'; the adjustments participants believed they had made following their cancer experience; how they knew they were making such adjustments and how they coped with these; challenges faced when attempting to adjust; and the feelings evoked when reflecting upon the adjustment process. In line with the grounded theory approach, the interview schedule was revised after every three interviews had been initially coded and analysed. This followed theoretical sampling principles, as the interview questions became more focused upon the emerging concepts and categories (Corbin & Strauss, 2015). This cyclical process of data collection and analysis resulted in four interview schedules at study completion (see Appendix 11 for all interview schedules).

2.6.3 Personal Details

Demographic information was collected from participants in order to provide the context of each participants' experiences. This context would aid data analysis, since it permits the researcher to go beyond the level of description of experiences and meaning, to be able to construct theory; individuals' actions and interactions may only be fully understood and explained when the context in which they arise is taken into account

(Corbin & Strauss, 2015). Participants' background information will influence how they interpret and assign meaning to events and actions, therefore it is pertinent to the data analysis, and my critical realist position, that this information is collected and considered. Furthermore, the American Psychological Association (2010) assert that a research sample should be appropriately identified and described since this is critical for science and psychological practice, especially when results are assessed, and comparisons made to replicated studies. The demographic information included details about the participant (e.g. age, ethnicity, social support, any mental health problems) and details about their experience of cancer and treatment (e.g. any previous experiences of cancer, site of HNC, any treatment received for HNC, and any receipt of psychological support; see Appendix 12 for full details collected).

2.6.4 Recording and Transcription

Each interview was audio recorded with a Dictaphone to allow transcription of the interview later. After each interview, the data was transcribed by a transcription service, following the signing of a confidentiality agreement between the researcher and the transcriber. The electronic audio file of the interview was stored on an encrypted data stick and was transferred to the transcription service via encrypted email. The transcriber was instructed to replace any identifiable information with generic information throughout the transcription process e.g. names of places, individuals, hospitals, clinicians would be replaced with 'name', 'Dr X' etc. Transcription services were used due to time constraints. Following the receipt of the transcription, the original audio files were played and transcriptions read simultaneously to ensure transcription accuracy and for the researcher to become immersed within the data.

2.7 Analysis

2.7.1 Using Computer Software

Computer software can be used to facilitate qualitative data analysis; NVivo is a computer software program compatible with many aspects of grounded theory methodology (Hutchinson, Johnston & Breckon, 2010). Some researchers have highlighted concerns regarding the use of computer software in qualitative data analysis, stating that it may distance the researcher from their data, and exert pressure on qualitative researchers to favour breadth and volume of research over depth and

meaning (St John & Johnson, 2000). However, several benefits of using such software also exist, for example, increasing the flexibility of coding systems, saving the researcher time from engaging in tedious clerical tasks, and providing efficient management of data (Bazeley, 2006; Kelle, 1997; St John & Johnson, 2000). Furthermore, Kelle (1997) suggests that concerns raised regarding the biases that may arise from computer software use are overemphasised when use is limited to coding and retrieval tasks. Use of software for ‘theory building’, however, may result in analysis distortion if methodological prerequisites are not followed.

Corbin and Strauss (2015) echo some of these concerns regarding researcher’s attempts to get the computer program to do the ‘thinking’. Overall, Corbin is an advocate of sensible use of computer software to aid qualitative data analysis, as it can be used to record, organise and sort through data, making this easier and more efficient, thus freeing up the researcher’s capacity to engage in creative and thoughtful analysis (Corbin & Strauss, 2015). With this in mind, the methodological guidelines set out by Corbin and Strauss (2015) were closely followed; asking questions of the data and engaging in constant comparative analysis. NVivo was primarily used to store, organise, and retrieve data and coded concepts, and to construct and organise memos.

2.7.2 Analysis Process

Interviews were transcribed and analysed after every three participants. This created a cyclical pattern of data collection and analysis, which allowed for the interview schedule to be reviewed and refined after every three participants had been interviewed (see Figure 10 for a diagrammatic representation of the research process). Alternating between data collection and analysis allows for theoretical sampling, and also serves to verify developing hypotheses (Strauss & Corbin, 1990).

The transcripts were initially coded using open codes; all coding was completed using NVivo computer software. This involves breaking down the data and closely examining it to identify and delineate the words and concepts that appear most important in understanding the participants’ meaning within the raw data (Corbin & Strauss, 2008). Initially, the codes were quite descriptive, though these became more abstract and explanatory as analysis continued. Open coding was completed on a sentence-by-sentence basis to be truly inductive, thus reducing the impact of any of my biases or

assumptions (Corbin & Strauss, 2015). Occasionally, ‘in vivo codes’ were used, whereby quotes from participants were used as concept labels or codes since they presented and described a concept very well and did not require interpretation (Corbin & Strauss, 2015). Axial coding was used simultaneously with open coding to describe how the emerging concepts and categories relate to each other (see Appendix 13 for a coded transcript example).

Strauss and Corbin (1990) describe that there are two basic analytic strategies that are used throughout the coding process; the asking of questions, and making comparisons. Asking questions of the data can be a particularly helpful starting place for qualitative analysis as it helps the researcher to understand the participants’ perspectives (Corbin & Strauss, 2008). Sensitizing questions were asked of the data, such as “what is going on here?”; theoretical questions, such as “what would happen if...?”; and practical questions, such as “which concepts need further development?”. Asking theoretical and practical questions of the data also helped to inform what theoretical sampling was required as analysis progressed (Corbin & Strauss, 2015). Throughout analysis constant comparison was used to identify similarities and differences in data extracts and instances to develop and elaborate upon the dimensions and properties of the concepts and categories that emerged from the data. This enabled me to develop a deeper understanding of the concepts and categories, and allowed me to differentiate them from one another (Corbin & Strauss, 2015). Through constant comparison, codes and concepts were grouped together to form higher-order concepts and categories, which were more abstract (see Appendix 14 for descriptive themes). Negative cases were also searched for (cases that do not fit into the developing concepts) as this helped me to consider alternative explanations and to fully explore the developing concepts. Corbin and Strauss (2015) suggest that negative cases add richness to findings since they highlight that life is complex and not all instances will be explained by one explanation.

To integrate the concepts and categories into theory, a core category was identified using Strauss and Corbin’s (1990) guidelines (Appendix 15). The core category represents the main theme of the research, has the greatest explanatory power, and links to all other categories (Corbin & Strauss, 2015). Diagrams and memos were used to explore and understand the links between concepts and categories (see section 2.7). Theory consists of relationships between a set of concepts that offers a plausible

explanation of the studied phenomena – ‘explanatory’ links differentiate theory from description (Corbin & Strauss, 2015; Strauss & Corbin, 1990). The theory was then validated by returning to the raw data and identifying evidence that verified the proposed theoretical relationships. This may be considered to complete the ‘grounding’ of the theory (Strauss & Corbin, 1990).

2.7.1 Memos and Diagrams

Memos and diagrams were used throughout the analysis process to track and order thoughts regarding concepts and the relationships between them (see Appendix 16 for examples). Memos were created and stored in NVivo. Corbin and Strauss (2015) emphasise that memos are an important analytic tool since they preserve the internal dialogue of the researcher when developing concepts and the relationships between them, thus mapping out the changes in thinking as analysis progresses. Memos contain the researcher’s interpretation of what they believe the data reflects (Corbin & Strauss, 2015). Writing memos is seen as a key part of theory building since they detail the identification, development, and dimensions of both concepts and categories. Memo writing also facilitates the researcher to ask questions of the data and to make comparisons. Perhaps most importantly, memos help the researcher to progress from lists of concepts and categories, to exploring relationships between them, to generating an integrated theory in which categories have explanatory links (Corbin & Strauss, 2015). Diagrams were also utilised within theory generation; these were particularly helpful for exploring the logic of the proposed relationships between categories (see Appendix 17 for diagrammatic theory development). Diagrams are conceptual visualisations of data which help the researcher to work beyond the descriptive level – at a more abstract, conceptual level (Corbin & Strauss, 2015).

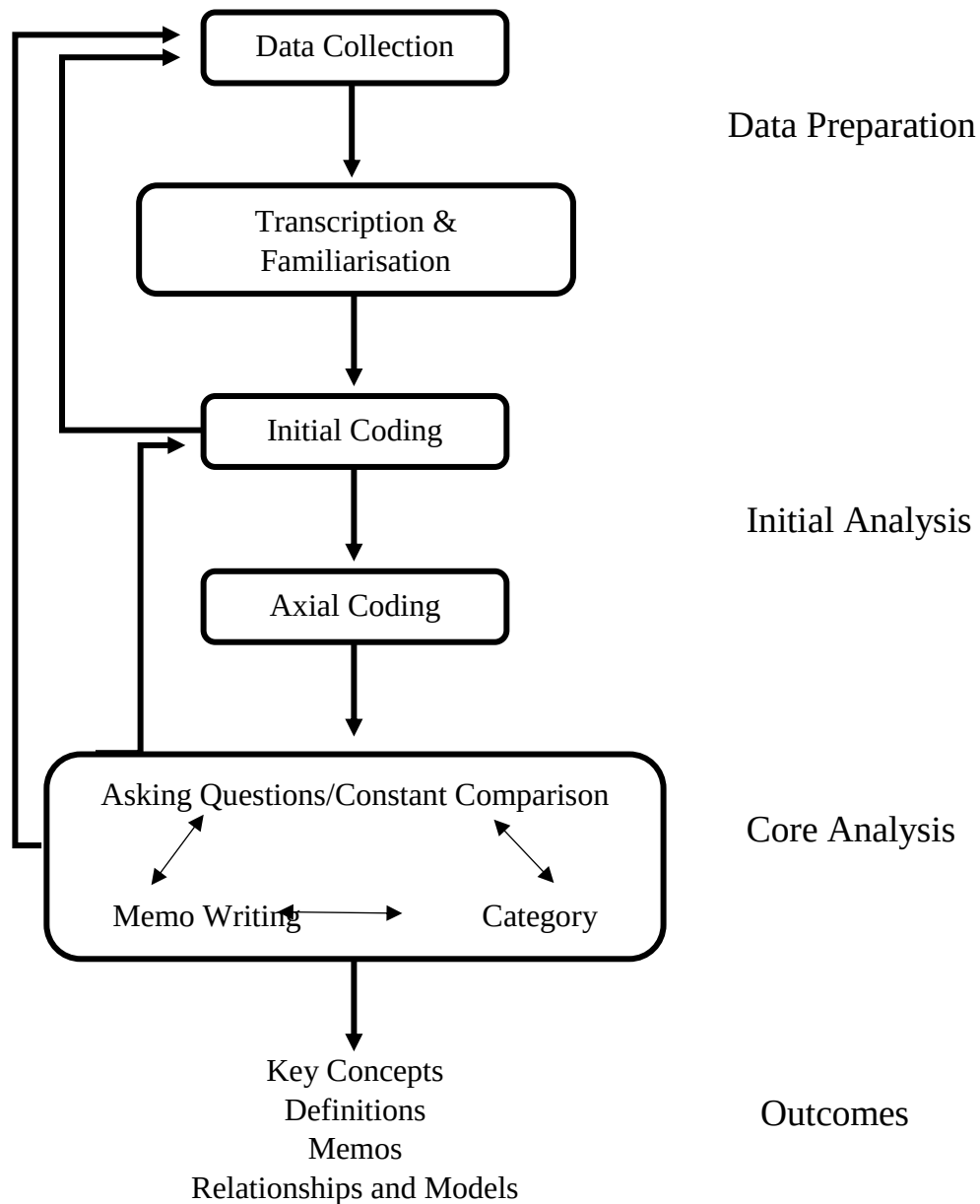


Figure 10. Grounded Theory research process adapted from Pidgeon & Henwood (1997).

2.7.2 Reflexivity

Since critical realism accepts that reality is imperfectly apprehensible, it requires researchers to critically examine factors that may have influenced the ‘reality’ represented in the data collected (Hall & Callery, 2001). Researchers working from a critical realist position, and with grounded theory methodology are encouraged to make explicit their relationship with the research process and material (Hall & Callery, 2001; Madill, Jordan & Shirley, 2000). I was aware that my previous experiences,

assumptions and expectations would influence data collection and analysis, and that I must be mindful and aware of these influences. Reflexivity is the practice in which the influences on research are explicitly recognised (Lincoln, Lynham & Guba, 2011). These include the influence of the researcher on the research process, and of the research on the researcher. Reflexivity is encouraged within grounded theory as it increases the robustness of the research by making the researcher position transparent (Engward & Davis, 2015).

Corbin and Strauss (2015) argue that the research both reacts to, and influences participants (and vice versa) within interviews. It is therefore important that my relationship to the research topic is openly acknowledged. I am a 29-year-old British female conducting this research as part of a Doctorate in Clinical Psychology qualification; I am currently employed as a trainee clinical psychologist. I do not have any clinical experience of HNC, though my mother had a large tumour removed from her neck, and therefore my interest in the area comes from personal experience. Through my personal experience I became aware that the psychological impact of HNC, and its treatment, is a neglected topic – focus appeared to me to be firmly placed on the physical management of removing or reducing the tumour. I witnessed my mother struggle to complete some of the most fundamental human functions (e.g. swallowing without choking, speaking, and breathing), and saw the challenges she faced in adjusting to these new limitations. My interest in this research was driven by the desire to develop an understanding of the process which individuals may go through when attempting to adjust to such experiences. I was aware of my own assumptions, for example, the negative impact HNC can have on physical functioning and one's ability to maintain an active lifestyle. From my professional interest in the research topic, as a trainee clinical psychologist, I am interested in using research methods to develop existing (or possibly in this case new) psychological theories that can be applied in clinical practice to support individuals to regain or develop their psychological wellbeing.

Strauss and Corbin (1990) suggest that drawing upon personal experiences may be helpful for making comparisons at times throughout the analysis process, though the researcher must be careful not to assume that others' experiences have been similar to theirs. I aimed to remain mindful about my own assumptions and expectations to

minimise the influence these had on my data collection and analysis. To achieve this, I kept a reflective journal and frequently utilised supervision. Corbin and Strauss (2015) recommend that grounded theory researchers keep a reflective diary to record feelings, impressions, and self-reflections throughout the research process as this will help researchers to maintain some distance from their research material and to be consciously aware of when assumptions or biases may be influencing analysis. Within interviews I also strived to maintain a balance between my roles as a researcher and as a trainee clinical psychologist, as at times I felt a pull towards offering a therapeutic space to discuss participants' experiences. Support was offered when necessary to manage any difficult emotions that arose during interviews, and further resources for support were provided, though I remained mindful that the interview was as part of a research project to explore participants' experiences and understanding of the adjustment process that they had navigated.

Theoretical sensitivity is also viewed as a form of reflexivity (Hall & Callery, 2001). Theoretical sensitivity refers to "the ability to recognise what is important in data and to give it meaning" (Strauss & Corbin, 1990, p. 46). Research may be approached with varying degrees of theoretical sensitivity which may have been developed through reading literature, professional or personal experiences. I did not have any professional experience of HNC prior to this study, and my personal experience is described above. Regarding my theoretical sensitivity developed from literature, I did not conduct a full literature review as this was likely to result in 'unrecognised assumptions' associated with existing theories, which likely impede the development of the grounded theory. However, Strauss and Corbin (1990) recognise that researchers will come to a study with some background knowledge of the literature, which is important to be acknowledged, and may be used in various ways. A basic review of existing literature helped to develop my theoretical sensitivity, especially literature which used little interpretation and satisfied itself with providing accurate descriptions of experiences and individuals' reality (e.g. Lang et al., 2013).

2.8 Quality Evaluation

The validity and quality of a study refers to the degree to which it is accepted as sound and legitimate to those with an interest in the findings (Yardley, 2015). Therefore it is

important to evaluate these aspects so that the study and its findings may be viewed as trustworthy and useful. Traditionally, scientific studies have been conducted from a positivist position using quantitative methods which aim to obtain ‘objective’ knowledge (Yardley, 2017). Within quantitative methods, to conduct a ‘valid’ study researchers seek to minimize or eliminate any influence that they may have on their data and analysis. However, qualitative research methods, and their underlying epistemology, accept that the researcher plays an active role in the research process and inevitably influences both the data collection and analysis – to maintain validity in qualitative methods, the researcher aims to be transparent about these influences rather than attempting to eliminate them (Yardley, 2015). Criteria for establishing and evaluating quality in quantitative studies are therefore not appropriate for evaluating quality within qualitative studies since research studies must be evaluated by the standards contained within their epistemological assumptions.

Madill et al. (2000) state that concepts of objectivity and reliability are not helpful in the evaluation of qualitative research. However, other researchers (Morse, Barrett, Mayan, Olson & Spiers, 2002) disagree, stating that reliability and validity should be reclaimed by qualitative researches by implementing verification strategies within the research process, and that these remain appropriate concepts for attaining rigor (described as trustworthiness in qualitative studies). Leung (2015) suggests that within qualitative research, validity should refer to the appropriateness of the research process, data, and methodological tools to the research question, and that the concept of reliability would be better focused on consistency rather than replicability within qualitative studies. It appears that there is consensus that quality evaluation is necessary for qualitative research, though there is little agreement regarding what this evaluation should consist of (Corbin & Strauss, 2008, 2015). This is perhaps complicated by the fact that it is difficult to identify quality criteria that would apply to all qualitative studies since there are various possible approaches to qualitative research, all based upon different assumptions and methodological procedures (Yardley, 2015). Furthermore, the quality of a study may be conceptualised in different ways; focus is either placed on methodological rigor (conduct of the research process), or interpretive rigor (trustworthiness of interpretations). However, Cooney (2011) suggests that both the process (methodology adherence) and product (interpretations/theory) must be considered when providing judgement on the credibility and quality of a grounded

theory study. Corbin and Strauss (2008) also suggest that as consensus is elusive, each qualitative method should have its own set of evaluation criteria. Several published criteria were considered for use in evaluating this study: Corbin and Strauss (2008, 2015); Charmaz (2006, 2014); Chiouitti and Piran (2003); and Cooney (2011).

I decided to use Corbin and Strauss' (2008, 2015) criteria, since these offer an evaluation of the 'credibility' of the study. Their criteria are specific to the grounded theory approach and are consistent with the epistemological position that I have taken. Credibility of a study, as described by Corbin and Strauss (2008), indicates that findings are trustworthy and believable as they reflect the participants', researchers', and reader's experiences with a phenomenon, though the explanation and theory are only one possible 'plausible' interpretation of the available data (compatible with a critical realist position). Furthermore, Corbin and Strauss' criteria evaluate both the methodological and interpretive aspects of the study to provide a judgement of credibility.

Corbin and Strauss (2015) assert that good quality grounded theory research has several characteristics, such as: resonating with the reader's and participants' experiences of a particular phenomenon; being interesting, clear, and logical; providing insight and showing sensitivity; and being both scientific and creative. Corbin and Strauss (2008, 2015) also suggest that specific conditions are also required to foster quality research, for example, maintaining 'methodological consistency' (Morse et al, 2002); ensuring that the research question and methodological components fit together. Cooney (2011) suggests that since rigor is built in to the grounded theory method (through the constant comparative analysis), correctly applying the methodology is the most important factor for ensuring quality within a grounded theory study. Other conditions include self-awareness and creativity (Corbin & Strauss, 2008, 2015). Throughout conducting this study I endeavoured to meet these conditions (see Appendix 18).

Corbin and Strauss (2008, 2015) developed their criteria by drawing on multiple sources. The criteria for evaluating this study are presented below as questions, as Cooney (2011) suggests that criteria in the form of questions enable novice researchers to more effectively audit their work and demonstrate its credibility. The questions are

presented under criterion headings. Questions relating to methodological consistency (presented in Corbin & Strauss, 2015) have also been incorporated.

- *Fit*
 - Do the findings fit with the experiences of the researcher and participants?
 - Do the findings resonate with professionals for whom the research was intended?
 - Do the findings “ring true” to the participants?
 - Was feedback gained from professionals and were changes to the theory made based on this feedback?
- *Applicability*
 - Do the findings offer new insights?
 - Do the findings add knowledge to the clinical psychology profession?
 - Is the core category sufficiently broad so that it can study other populations and similar settings?
- *Concepts*
 - Are the findings organised into concepts?
 - Are the concepts developed in terms of their properties and dimensions?
 - Is there density and variation within the concepts?
- *Contextualization of concepts*
 - Do the findings and concepts incorporate context?
 - Does the context presented allow readers to understand why certain meanings were assigned to events or experiences?
- *Logic*
 - Is there a logical flow of ideas?
 - Do the findings ‘make sense’?
 - Are methodological decisions made clear?
- *Depth*
 - Do the concepts have depth?
 - Do the findings and concepts include rich descriptions?
 - At what point did data collection end or a discussion of saturation end?
- *Variation*
 - Do the findings include variation?

- Are there examples of cases that don't fit the pattern?
- Is there mention of negative cases and how this data was managed?
- *Creativity*
 - Are the findings presented in a creative and innovative manner?
 - Does the research say something new or put old ideas together in new ways?
- *Sensitivity*
 - Did the researcher demonstrate sensitivity to the participants and data?
 - Were the concepts generated from analysis of the data (theoretical sampling) or derived through the literature before data analysis?
- *Use of memos*
 - Is there evidence or examples of memos?

Chapter 3. Results

3 Extended Results

3.1 The Nature of Adjustment

All participants had an idea about what they perceived adjustment to be. For one this included engaging in purely physical adjustments (Peter), for example, changes in daily activities undertaken and needing to use a feeding tube. However, for all others, adjustment included both physical and psychological aspects:

“Always making sure I’ve got water on my desk at work because your mouth gets dry, then talking becomes more difficult. You know, you sort of, your tongue feels like its swelling up, sort of thing. Things like that, you know, just, not massive adjustments, but just things that you have to do” – Lawrence

Nevertheless, adjustment was described by all as a long-term process, due to the time taken to start to return to an acceptable range of functioning, and the numerous changes and challenges that must be overcome:

“It’s going to take a while for me to adjust to it all because there’s an awful lot going off” – Eve

Visible and non-visible (functional) aspects were specifically referred to when participants reflected on their adjustments, identifying both aspects as important and requiring adjustment:

“It takes a lot of adjusting to the disfigurement, with the bits you can see and the bits people can’t see” – Arthur

As mentioned within the journal paper, adjustment was seen to encompass all aspects of life. This appeared to be unexpected for some, and perceived to be misunderstood by others who have not had an experience of HNC (Arthur), however, for Bruce, who had not yet had his cancer treatment, the all-encompassing nature of adjustment was expected:

“We’ve had to come to terms with the initial diagnosis, it’s like a full freight train, isn’t it, when you first hear the diagnosis because it’s just not what you want to hear. And I’m having to think about what I’m going to do afterwards and how it’s going to change things because I’m going to have to adjust everything” – Bruce

Learning to cope and live with various aspects of change was also included within participants’ definitions of adjustment:

“Learning to live with the fact that you’re no longer the same person that you were before” – Lawrence

Sebastian identified a goal of adjustment, rather than the nature of it, describing this as:

“I suppose my target, my ambition through it all, was to get this, get it done, get better, get back to, not normality because it’s, normality, there is no such thing, but to get back to being well” – Sebastian

It seemed that all participants had developed their own understanding of adjustment, and what this encompassed, though some spoke about it in broad terms. Whilst some participants saw psychological adjustments and alterations in approach and thinking as important, some focused mainly on physical adjustments. All participants identified adjustment as making some change to their current situation. Whether participants focused on physical or psychological challenges was likely to influence how they engaged with different aspects of the adjustment process.

3.2 Modifying Your Relationship to the Changes Cancer Brings

As mentioned in the journal paper, this process underpinned all other processes involved in participants’ psychological adjustment to HNC. This modification of the relationship appeared effortful and conscious for some participants, and relatively natural and effortless for others. Within the acute stages (‘Survive mode’), participants may ‘battle’ against their changes and require assistance from others to do so (‘Instrumental support from others’). This may include battling to be able to swallow, talk, and having enough energy to move around. Once they either regained some of

these abilities (through recovery and rehabilitation) or generally felt better physically, the relationship with the remaining struggles may be reappraised (“Making a choice”). Processes such as “Developing own understanding”, “Acceptance” and “Talking with others” can start to prepare and shift patients to being able to live alongside and with the changes, which are then realised by “Making changes” which may allow for normality to be regained or redefined, with the addition of these new changes.

“Barriers to progress” may hinder the modification of the relationship to the changes, and some have the potential to send them back to ‘battle’ with the changes. Processes of “Managing emotions/distressing thoughts” and “Putting things into perspective” continue throughout the adjustment process, and also facilitate the modification of the relationship by stabilising emotional experiences. Although “Developing own understanding” appeared to be a process central to the adjustment process, it did not explicitly link to all other categories, and therefore could not be considered a core category. However, as a central process, it is explored under the core category of modifying relationships to cancer changes.

3.3 ‘Survive Mode’

This category referred to how many participants experienced the initial changes in their physical functioning as a result of the cancer or cancer treatment. This occurred in the acute stages of illness – pre-treatment, during treatment, and immediately post-treatment. Within this phase, a ‘battle’ was described in which participants needed to fight against their newfound limitations. Within this phase, Eve described feeling ‘stuck’ as she struggled to function and to feel better. Many difficulties were described as stemming from the cancer treatments and the subsequent effects on functions such as eating, swallowing and breathing:

“I was stuck in this sickly spell, this, well I didn’t exist. I was just a shell, I was hurting, I was in pain a lot with, I think it’s because of the fatigue and the not eating” – Eve

Participants engaged in different strategies to help them navigate this phase. Taking each day as it comes and setting small goals/milestones for recovery (regaining of ability and/or feeling physically better) were common strategies:

“You’ve got targets, you’re like your target, the major operation, then your target, the skin graft and the teeth out, and being able to walk” – Arthur

Considering how far to look ahead and plan was also considered in this stage. Three participants reflected on how they narrowed down their vision to focus on the present and immediate future as a way of getting through the struggle:

“You can’t look what’s round the bends, if you like. You know, what have I got in front of me, what have I got to deal with now? OK, let’s just deal with that. Try and be pragmatic” - Sebastian

This narrowing of vision was contrasted with still acknowledging the need to look a little ahead to plan and remain in control:

“It’s a hard one because you’ve got to think of stuff still, otherwise you’ll lose all control of everything” - Bruce

However, not all participants experienced it as such a battle. Peter describes how he found initial recovery to be an unpleasant experience as it contrasted sharply to how he felt before his operation, though did not ‘battle’:

“One day you walk into an operating theatre and you don’t feel particularly ill. When you come out ... you feel alright because they’ve dosed you up to the eyeballs. And then for about ten days, when you’re in the hospital, then you start to feel a bit grotty, you know, it’s not pleasant, but I mean you have to go through it” – Peter

3.4 Instrumental Support from Others

Participants reflected on how they relied on others to perform tasks for them whilst they battled with other effects of HNC and its treatment. This included during their hospital stay from nurses, and also family members, mostly spouses, continuing the support when they returned home. Instrumental support included direct caretaking, but also fulfilling roles that participants had previously held:

“I couldn’t have a proper wash, my partner had to wash me, she had to do my hair and that was really upsetting... I did it once and I didn’t realise and the water went down and it nearly choked me” - Arthur

“Yes, from being absent or being ill or, you know, being in a, upstairs in bed a lot and stuff like that. Then others had to step in, so my parents stepped in to help in certain things” - Sebastian

Some participants struggled with the notion of requiring support from others as they were usually self-sufficient (Bruce, Arthur), or provided support to others (Eve), and others simply handed over responsibility to medical staff, stating that they were in the best position to support their recovery since they know best (Peter):

“Yes, and, well people were already sorting it on my behalf with the hospital, you know, that’s the sort of thing that you have to look at really” - Peter

The level of support required from others varied between participants, but the concept of needing others to fulfil instrumental tasks for them was present in all interviews. Several participants described how they had tried to do things for themselves and discovered that they were no longer capable, at least in the short term, and therefore required others to do it for them.

3.5 Making a Choice

Participants engaged in ‘making a choice’, which occurred when they had overcome some of the initial challenges associated with acute illness. This process appeared to be an implicit one when the choice to change was gradual, resulting from the cumulative

effect of various differences. However, for some, it was a cognitive choice, arising from a ‘turning point’ moment in which participants suddenly realised the need to change. Lawrence describes how he reacted in a way that he would not have previously when his son did not follow instructions, and it was his son’s reaction that highlighted to him that he was now responding differently. In this moment, Lawrence made a choice to change things:

“Saying to the kids, for example, pick that up off the floor you’ve just dropped, walk out the room, come back and it still being there and flipping my lid. And then looking at (son) looking at me like, wow ... that was the point; OK, this is not you, this is not how you dealt with things before, something is not right here” – Lawrence

The ‘making a choice’ process occurred early on for some, and later for others. In those whom it appeared later for (Lawrence, Sebastian), they had returned to some type of physical normality and had returned to work, though they then experienced the psychological impact of having experienced HNC, finding it difficult to manage emotions and subsequent reactions. In particular, Sebastian described that an earlier strategy of dealing with things as isolated factors was no longer working:

“Mentally I was fine but it wasn’t until I went back to work ...it was explained to me that you’ve dealt with it, this separate segmented, right, what’s next, what’s next, what’s next, what’s next? And you’ve done that and then you’re having, now all this just crashed over me ... it brings up all the other things that have gone off in my life” – Sebastian

Although the way in which the need to make a choice was realised, and the choice that was made, differed between participants, it was a process that was present for all. Peter, who perceived that he did not need to make any adjustments (other than physical adjustments), still appeared to have made a choice to simply view his life as “on hold” until he regained his functional abilities (eating and energy). This choice to ‘wait’ likely influenced his subsequent adjustment to HNC.

3.6 Developing Own Understanding

This category referred to a process that all participants engaged in after the ‘making a choice’ process. Participants used various types of information to develop their own understanding of their physical limitations, and emotional struggles. This understanding helped to diminish some of the frustration faced in relation to these experiences. Resulting from the development of their understanding, participants reflected on feeling able to start to alter their expectations of themselves. In particular, Lawrence explained the importance of his understanding of the different ‘road’ he was now on, which subsequently influenced how he approached difficulties:

“I was trying to get back to a road that I no longer could be on because I have had cancer. And because I couldn’t get there, I was frustrated with myself because I couldn’t get back to somewhere, until it actually clicked, which sounds obvious when you think about it. But until it actually clicked that that person doesn’t exist anymore, I can’t be on that road anymore, I’m now on this one” –

Lawrence

Recognising the impact and magnitude of their cancer and its treatment, and the subsequent time taken to recover was also a component of ‘developing own understanding’. Some participants explained that they found the prolonged time taken to recover to be surprising and tedious, despite being informed of the expected recovery time. Others reflected on how they needed to learn about the function of different parts of their anatomy, and thus realising the impact of this being removed:

“I am slowly coming to recognise that I’m not going to be able to do that, just purely and simply because of what’s happened. Every time we go to the hospital I say to (wife), I don’t really recognise how big an operation it was that should have made the difference it seems to have made to my life” – Walter

‘Developing own understanding’ also included an aspect of relearning their own personal limits and abilities; developing understanding of current functional ability, and what it may return to in the future. Some of this relearning occurred through trial-and-error:

“You try and run before you can walk and you can’t, you can’t. As much as you want to, as much as you think you can, you can’t, and sometimes you have to be reminded of that” – Arthur

Bruce described an active process, and the effects, of coming to an understanding about his planned HNC treatment and its anticipated effects, explaining that he believed that it would help to dampen any difficult emotions that may occur as a result of subsequent physical limitations:

“The more you can adjust in advance, there’s truth in the statement of, forewarned is forearmed. The more you can prepare for it, the lesser of an impact it’s going to take, because I was expecting this” – Bruce

An understanding of HNC and its effects can help to diminish some of the psychological difficulties that patients encounter in response to their physical limitations and emotional responses, as ‘knowing why’ is viewed as a comfort. This category therefore highlights the need for accurate and timely information for HNC patients to facilitate this understanding process. However, a quote from Arthur highlights the difficulty in providing this optimum amount of information to be helpful and facilitate understanding, but not too much to be upsetting:

“I know a lot of people don’t want to know everything but I do, you know, I needed to know what, you know, what the possible signs, you know, was going to happen to me and stuff like that. I needed to know that. But saying that, when I’d had the operation and had the skin graft and all that, when I went to the preliminary for the radiotherapy, my partner thinks they told me too much because that upset me as well” – Arthur

3.7 Acceptance

As stated in the journal paper, it appeared that some of the meaning assigned to this category by participants may include an aspect of resignation as they had simply been faced with evidence that they were not able to engage in certain activities, be able to complete some functions, or have to contend with some challenges that others do not.

Arthur also describes that acceptance about his decision to undergo his disfiguring surgery may also be reached through a process of considering the disastrous consequences if he had not consented to this cancer treatment. In this way, this view of acceptance may appear relatively simplistic or may be a reflection of participants' difficulties in articulating what acceptance is, and choosing to use examples:

“Just accepting that without this I wouldn't be here and you have choices that, I'd rather be here than not, you know. If it means having this disfigurement and being here, because I'm still the same man, still me” – Arthur

This difficulty in articulation and understanding of an acceptance process is also highlighted by Walter, who describes a conflict between trying to accept changes and trying to fight against them, for which he advocates both:

“You've got to accept it but you can't, you've got to try and fight it as well. If you can, deposit it. There are certain things that I know that I'm not going to be able to do anymore” – Walter

The emotional effect of engaging in an 'acceptance' process was described by some participants. This included an acknowledgement that 'acceptance' did not rid them of their difficult emotions, though it did render them less distressing. It was noted that participants who were most able to articulate the resultant effects of acceptance had engaged in psychological therapy, suggesting that understanding the function of acceptance may be difficult to arrive at without assistance:

“You can't stop those inner feelings. So it's a case of, how do I adjust to let those be part of what I am and accept them for what they are?” – Sebastian

Acceptance seemed to be a difficult concept for participants to describe and define, choosing to use examples to demonstrate how they had engaged in the process and what its effects were. As mentioned in the journal paper, all participants referred to this concept, suggesting that it is not simply a product of therapy. However, those who had received some type of individual psychological intervention found it easier to articulate the process and how they engaged in it. This suggests that whilst this process was

present for all participants, it may be used differently depending on whether they have received additional psychological support or not.

3.8 Talking with Others

Talking with others was a process which was reflected on by all participants, though they utilised this differently. Several participants emphasised how important this process was for them, as it helped them to process some of the emotions that were attached to their experiences:

“It’s important to talk. I think if you bottle it all in, everything in, then I think you’d be in a worst state mentally because it’s all in there, you need to get some of it out. It’s still hard, you’re still fighting it, but it allows you to cope, get through everyday life and get through a bit better” – Arthur

Contrasting views existed between participants when discussing the need to talk to family and friends about their experiences, as some reflected on an attitude of ‘getting through it together’ with family members as a result of sharing the HNC experience, however, some promoted their family as fulfilling a more a passive comforting role:

“They’re a comfort, you know, they always have been, but I’m not aware of anything specific I can put my finger on” – Lawrence

Some participants also discussed how they chose not to talk to people about some of their experiences. This occurred for different reasons, including not wanting to burden others and not wanting to deal with others’ reactions. The decision not to talk included an element of choosing what to share with whom. One participant (Peter) explained that he did not need to discuss emotional responses to his cancer as he did not experience any. Conversely, another participant (Arthur) described how talking to friends and family helped him to process his emotions, though he felt more comfortable talking with his female friends and partner about some topics (e.g. concerns about hair loss) than male friends. As described above, some feelings and experiences were not shared with family members in the interest of not burdening them, however, these feelings were sometimes shared with individuals outside of the participant’s everyday context:

“In my case with (therapist) anyway, I said this to her politely; you’re not part of my life, I may never see you again. So if I tell you something here, you’re not going to sit at the, you know, at the Christmas dinner table and something comes up and you go, oh I remember (Lawrence) said something, look at me. I can be completely open and relaxed ... It’s good to have somebody who is outside of your normal life to admit your fears, etc., to” – Lawrence

Talking with peers and attending groups was reflected on by six participants. They described this as helping them to validate their own experiences as it had enabled them to discover that others had similar difficulties, whereas previously they had felt that they were alone in their struggles or struggling disproportionately compared to others. Attending groups also offered a sense of ‘community’ and facilitated participants starting to learn how to talk about their experience. It also offered a space to share strategies for overcoming different challenges. Talking with peers occurred at different time points for participants. Some participants engaged in this opportunity as soon as it was offered and felt that this was a useful experience. Sebastian reflected on how he did not wish to engage in this process initially, though later found it to be beneficial:

“I didn’t want to be around people with cancer ... I don’t feel I need to talk to anybody else who’s gone through this or had this It wasn’t until after I got the clear ... then I went to this group, that was with lots of people with different types of cancers ... but then talking to people, and it was at that point I realised that it was really helpful” – Sebastian

In addition to talking with medical professionals, talking with peers offered an opportunity to discover what ‘normal’ experience is. When this ‘normal’ experience was shared between peers, patients, and their family members, it appeared to help the participant and their family member develop a shared understanding of the difficulties faced, and the reality of them.

3.9 Making Changes

This category refers to the process of making changes to practical approaches or thinking styles that participants engaged in when adjusting to their newfound challenges. For some changes this was an implicit process, and some were driven by effortful, conscious problem-solving.

As part of increasing self-compassion, three participants described how they had developed a better understanding of their bodies and had learned to listen to them. Sebastian discussed this in the context of noticing when he is feeling physically unwell and learning to approach this differently instead of trying to ‘push on’ like he had previously:

“You get a cold and, you know, you realise, you sort of think, you know, I just can’t, I’m just tired. So I need to listen to my body, I need to listen to what’s happening, go to bed early if needs be” – Sebastian

As stated in the journal paper, participants engaged in a process of making practical changes to deal with and manage some of the challenges they faced as a result of their HNC. Some of these changes appeared small, but still impacted upon how participants adjusted to their HNC. These were often aimed at directly counteracting some of the effects of HNC treatment, for example fatigue:

“Yesterday I couldn’t hardly do anything, but I kept trying to potter round. So I needed some potatoes, so I thought, put me shoes on, not my slippers, just go and get some potatoes because it will get me out and do. So it’s ongoing” – Eve

However, there were contrasting views on how fatigue was managed; some participants avoided attempting to engage in some activities, and some continued as they had before and only stopped when they physically could not continue due to fatigue.

Some practical strategies were aimed at distracting from unpleasant effects, and to enable participants to experience some enjoyment in their life, which was considered to be a very important aspect:

“My friend gave me a guitar, and I can’t see the notes and chords, but by just playing or trying to play, again, it just takes your mind off what you’re going through. And if it’s only just five/ten minutes a day, it’s just, it’s just forgetting about all of what you’ve gone through or what you look like. It’s enjoying something else and that’s massive to me” – Arthur

Many of the changes participants reflected on seemed to be designed to enable them to continue to engage in aspects of their lives that are important to them, and those which they define themselves by. They suggested that the changes made were in the interest of staying the same person and retaining a sense of normality. In this respect, some of the changes simply reflected a change in intensity or level of involvement that changed, rather than their fundamental approach:

“My eldest son used to play a lot of football, so as soon as I could, wrapped up in loads of layers of clothing, you still go and stand and watch the football or sit in the car and watch the football if I couldn’t stand up and watch it. Trying to get back to being as much of the person, as a normal dad, for want of a better word, and husband that I was beforehand” – Lawrence

A change in life focus was reflected on, apparently brought on by being faced with one’s own mortality. Three participants described how they now focus on enjoying life in the present. Sebastian specifically reflected on this and how he has changed his focus from working very hard to retire at 65 and be able to enjoy himself *then*, to ensuring that he enjoys himself *now*:

“Stopping myself being goal driven towards being sixty and wishing your life away, if you like, to actually, I mean that in a, wishing the time away, but actually, no, just stop that. That’s going to happen anyway, you know, what’s next? What’s happening this weekend, what’s happening today” – Sebastian

Changed outlook, appreciation and life focus was implicit for some as they reflected having not consciously chosen to change these; they simply noticed the changes, and for some it was a conscious choice to change. However, two participants specifically stated

that although they may approach things differently, they do not feel that they have changed their outlook on life.

3.10 Redefining or Regaining Normality

As stated in the journal paper, many participants regained a sense of normality through being able to return to activities and pastimes that they had previously enjoyed and valued. However, other elements also indicated to participants that they had returned to normality. For example, Lawrence described how his return of his “bad habits” such as putting things off, was indicative to him that he had returned to ‘normality’:

“I certainly, am getting back into old bad habits, I know I am, which part of me says, well accept that because you go back to living, without worrying about it... thinking, I’ve got plenty of time to do stuff again, I haven’t got to cram everything in now because I might not be here” – Lawrence

In contrast, some normality was redefined as a result of experiencing ongoing changes and effects of HNC. Alice describes how she had resumed going out for food as a social activity, but that this activity indicates that normality has been redefined by the restrictions on her food choices and resultant enjoyment level:

“We do go out, we have been out and we do go out and we find places where we can have, well other people can have a meal and I can have soup, you know. But it’s not quite the same, I do find myself sitting there while they’re eating and thinking, oh, you know, this isn’t great” – Alice

Normality was redefined to different degrees; as discussed above, Alice’s normality was redefined to include having soup when dining out. For Alice, this was a relatively small change that was permanent. Peter described his life as similar to what it had been, though he had also incorporated a redefinition of his normality at present to include his enjoyment of life being “on hold” and currently remaining “tied” to his house as a result of being dependent upon a feeding tube. This redefined normality resulted in him appearing relatively content with his current situation, however, this was an interim

normality for Peter as he did not perceive it to be his definitive normality. Peter viewed normality as very different in the future:

“Life is going on pretty much as it used to, apart from the fact that I’m stuck more in here ... it’s on hold for like six months, then I can start making progress ... just go and drive around all over the place, seeing all sorts of places, and just generally having a good time. And as long as I can eat and drink without having to take all this, then we’ll be fine, we’ll have a good time” – Peter

For one participant (Eve), her redefinition of normality resulted from her attempts to regain a sense of normality. As part of this process she had learned to ask others for help, and to push herself to say ‘yes’ more. Consequently she gained more confidence and engaged in activities she described that she never would have before HNC:

“The person I was before would never have gone and done that exam, would never have put herself in that position in the first place. So in a way it’s helped me be this new person that I am” – Eve

Normality was also described by several participants as resuming as soon as they returned home from their hospital stay, or when their treatment had finished. They described this as an ‘automatic’ process:

“Once I came home, well I just came on leaps and bounds then, you know, in your own environment” – Marie

3.11 Barriers to Progress

This category referred to factors which hindered or prevented progress in adjusting to HNC and its effects. The enduring, constant nature of the effects was reflected on as a particular area of difficulty for participants as they often deprived them of the energy required to make positive changes. These effects were often unexpected and the emergence of various different unexpected effects was experienced as challenging:

“You think, oh, you know, I hope, I can see that I’m getting, feeling physically a bit better and, you know. Then you start fatiguing and falling asleep, and then things start dropping, hair starts dropping out and you think, here we go again” – Arthur

Several participants also commented on the speed at which they experienced the changes, especially in relation to surgery. They described how experiencing such a big change to functional ability was difficult to come to terms with, and that this impacted upon how they were able to process these changes:

“I remember thinking not long before, earlier that year we moved house and stuff, and carrying boxes and, you know, thinking, I feel really good, you know, I’m forty but I feel alright, you know. I feel quite fit and strong and healthy. And literally, within a few months, you could die. I remember that, thinking, lying in bed thinking, how can you have felt so really good, to the point of actually acknowledging, you know, in your head, how well you felt, and then not being well anymore” – Lawrence

With respect to timeframes in which different components of HNC were experienced, aspects of recovery occurring either too soon, or too late was also perceived as a barrier to adjustment. This seemed to be either due to feeling unprepared for the effects (e.g. being informed that radiotherapy effects will continue after treatment ceases at the last session of radiotherapy), or not feeling in control of one’s own situation. Arthur discussed how traumatic he found it when he saw his facial disfigurement “too early”:

“My partner didn’t think I was ready and I didn’t think I was ready to look at it as well. So that takes a lot of weeks, you know, I don’t know, every individual is different, but for me it took really to the latter end of the radiotherapy for me to look at it and that was by accident, which was very traumatic and upset me a lot, initially” – Arthur

As stated in the journal paper, fluctuations in HNC effects and resulting abilities and functions were reflected upon as barriers to progress. Specifically, these were most

problematic when participants were not able to understand or mitigate them even when after seeking professional guidance and advice:

“I can’t explain that, and there are certain things that that happens. I can one day have something and it would seem alright, then the next day I just can’t have it. And I’ve tried to read through the books that they gave me, the cancer, food after cancer, I have tried some of those things but they don’t seem to work for me”
– Walter

3.12 Managing Emotions/Distressing Thoughts

Most participants described how they needed to engage in a process of managing their emotions and distressing thoughts which arise as a result of their HNC experiences. Although these emotions may initially arise due to their current experiences related to HNC, they do not always remain specific to this:

“Sometimes it can be when I’m on my own and you then, you start thinking silly things, and, an emotion you know, you just think, I don’t know, you tend to think about your dad and your mum and your brother. I have gone through a really bad divorce as well, so things like that go through your mind and you just breakdown and start getting upset” – Arthur

However, sometimes these emotions were directly linked to the HNC effects. Several participants also described how difficult they found it to deal with some of these emotions, especially when the emotions experienced were particularly intense, or had not been a salient aspect of participants’ previous experienced:

“I don’t cry very easily. I have got more emotional lately, as it’s gone on” – Alice

Conversely, two participants described that they had not experienced any noticeable or problematic emotions in relation to their HNC and had “just got on with it” (George):

“I never felt terribly sad about it. I didn’t feel angry about it. It’s just one of those things that has to be dealt with” – Peter

Where emotions were present, most participants advocated for allowing themselves to experience their emotions, but to limit how much these are shown to, and shared with, other people. This decision to hide some emotional reactions was commented upon by four participants:

“After I had my treatment I was off work for three months, so everybody would go out to work and school and, therefore, you could sit there and whinge about life and have a cry if you wanted to or, you know, kick a cushion away if you wanted to do and scream, life’s not fair. You don’t do it when everybody else is in the house”
– Lawrence

Avoidance and distancing was used in managing reminders. This seemed to be difficult at times as the reminders were often prompted by the ongoing physical effects and limitations. However, participants reflected on how they avoided reminders where possible (e.g. television adverts for cancer support), and created distance from the physical reminders by not thinking about them too much when they occurred.

3.13 Putting Things into Perspective

This category referred to how participants placed their experiences in the context of what could have happened, thus it was labelled ‘putting things into perspective’. Participants described how the continuation of life was the most important element of their experience and as such, other elements such as physical limitations or disfigurement became less important when compared with the possibility of death. Some participants reflected on how they felt the need to explicitly acknowledge their negative experiences and mortality, which then enabled them to put things into perspective and to focus on the positives:

“I found the hardest thing is talking about death but you’ve got to talk about it ... it’s alright everybody said, look on the positive side, but you’ve got to look on the negative side as well” – Raymond

In addition to focusing on the importance of retaining life, some participants also reflected on how they placed their lost or diminished abilities in perspective by ensuring

that they also acknowledged what abilities they have maintained. Bruce reflects on this in anticipation of losing his ability to speak and taste following surgery:

“You’ve got to try and think as positive as you can, even if you can’t think positively about the actual thing itself ... I shall still be a little cook, I won’t be able to taste my food, so god knows what it will taste like but it won’t be my problem” – Bruce

Bruce’s engagement in this perspective taking, before surgery, highlights that this process occurs throughout the entire adjustment journey, both in preparation for treatment, when dealing with the effects of treatment, and in later recovery stages.

Many participants also placed their experiences into perspective by considering that there are things that may be worse than their cancer and its effects. Included in this was the idea that other people are in worse positions:

“There’s so many people who are so much worse off than me, that you can’t wallow in that much self-pity. You’re allowed a little bit but, you know, I’m not the world’s worst off person” – Lawrence

At times participants referred to this process of ‘putting things into perspective’ as “thinking positive” and highlighted the potential negative consequences of not engaging in “positive thinking”:

“You’ve got to do, otherwise you end up, it swallows you. You end up in a big black hole that swallows you up and might not even spit you back out. It’s not an area to go in to” – Bruce

Maintaining hope for the future was also included within this category as participants reflected on how they gained perspective of where they are now, acknowledging their current limitations, and where they would like to be in the future and maintaining hope that it will be better and that abilities would be restored:

“I used to love driving ... take the car to the top of the street, which I did do, and I thought, no, you’re not ready yet. So I parked the car up and left it for another

month again, another month or two. And then went onto driving, that's the biggest, to be honest with you, the biggest joy, thinking, I know in the summer I can drive" –
Raymond

Chapter 4. Discussion

4 Extended Discussion

4.1 Fulfilling Needs

Participants highlighted that in initial recovery and adjustment, any changes were made only because they were physically no longer able to function as they had previously. Many participants explained that so many personal resources are expended to just exist and live (fighting against pain, difficulties swallowing and speaking) that no resources were available to consider psychological changes and needs. Eades et al. (2009) suggest that weight loss and loss of energy, strength and muscle endurance may place HNC patients at risk of adjustment difficulties. As stated in the journal paper, our model may be understood under the framework of human motivation and the hierarchy of needs, posited by Maslow (1943, 1970).

Maslow (1943) suggested that fulfilment of basic physiological and safety needs may be disrupted, or these needs are heightened, by the occurrence of illness. As such, these newly unmet needs then motivate patients to engage in behaviour which may get them fulfilled. This is reflected within the ‘survive mode’ category of the proposed model; participants are focused on meeting their basic needs for food, water, and safety. Once these needs are sufficiently met, or their intensity is lessened, higher-order needs may emerge, such as esteem (e.g. need for dignity and independence), cognitive (e.g. need for knowledge and understanding), and aesthetic needs (e.g. appreciation for beauty). The fulfilment of these higher-order needs may also be observed in my proposed model: ‘making a choice’, ‘practical strategies’ and ‘managing emotions/distressing thoughts’ may be conceptualised as attempting to fulfil esteem needs; developing own understanding’, ‘acceptance’, and ‘putting things into perspective’ may be conceptualised as processes to fulfil cognitive needs; and changing their ‘outlook on life’ may be understood as attempting to meet aesthetic needs. Participants may also be perceived to engage in self-actualisation (realising personal potential and seeking personal growth) as part of the ‘redefining or regaining normality’ process. Kenrick et al. (2010) suggest that since each individual is unique, they may achieve self-actualisation via a variety of directions. This is also demonstrated within my findings as participants described being motivated by different aims e.g. aim to enjoy life more, to regain fitness, and to focus on important relationships.

The 'barriers to progress' may also be understood under this framework, and may be conceptualised as factors which prevent needs from being met, through the lack of provision of support from others, or physical abilities and needs being compromised. Therefore, Maslow's Theory of Human Motivation provides one explanation for the processes (and movement between processes) contained within the proposed model.

4.2 Social Support and Effect on Families

As stated in the journal paper, various types of social support were utilised by participants throughout adjustment to HNC. Hegleson and Cohen (1996) described how these different types of social support may generally be useful within a cancer setting. They suggest that emotional support (listening, empathising and comforting) can help with patients' feelings of inadequacy by communicating that they are still cared for, valued, and loved. Informational support (providing information to guide or advise) can help to decrease confusion regarding the cancer trajectory, and instrumental support may help to offset the sense of loss of control experienced by cancer patients. Karnell, Christensen, Rosenthal, Magnuson and Funk (2007) suggest that social support may be particularly important in HNC patients due to the effects on speech, eating, and facial appearance. They suggest that emotional support from friends and family may help HNC patient to start to function again socially and foster a positive attitude about their post-treatment functioning. Additionally, instrumental support may also be beneficial; specifically in preparing food in a way that reduces patients' difficulties with eating.

Several authors suggest that the provision of emotional support was particularly desired and beneficial for cancer patients (de Leeuw, de Graeff, Ros, Hordijk, Blijham & Winnubst, 2000; Hegleson & Cohen, 1996; Rose, 1990). In HNC, Llewellyn et al. (2013) report that the use of emotional support is predictive of finding more positive consequences of HNC occurrence. Therefore, the availability and use of emotional support may help to facilitate a positive outlook and to reduce the impact of difficult to manage consequences of HNC treatment. Bloom, Stewart, Johnston, Banks and Fobair (2001) and Sultan, Fisher, Voils, Kinney, Sandler and Provenzale (2004) reported that the provision of instrumental support was associated with lower QoL in breast cancer and colorectal cancer patients, respectively. Both studies offer the hypothesis that patients with greater physical limitations, and therefore lower QoL, require more

assistance and thus use more instrumental resources. However, the provision of instrumental support may also hold an emotional support component (e.g. communicating caring, empathy, and acceptance), especially if this is provided by family or friends (Semmer, Elfering, Jacobshagen, Perrot, Beehr & Boos, 2008). Therefore, when this type of support is required due to physical limitations, it may have additional benefits to patients due to its emotional quality. However, this must be appropriately offered since it has been suggested that when offered indiscriminately, instrumental support may negatively affect the patient's autonomy and mood (de Leeuw et al., 2000).

Informational support may help to enhance patients' perceptions of control by providing ways to help them to manage illness and cope with symptoms (Hegelson & Cohen, 1996). It may also be helpful in counteracting the sense of confusion often experienced by cancer patients by helping the patient to understand the cause, course, and treatment of their cancer. Our study adds an extra element to this; demonstrating that understanding the reasons for physical limitations, resulting from cancer treatment, is also an important aspect afforded by the provision of informational support. Several authors suggest that this type of support is a significant contributor to the adjustment of patients regarding how they manage the effects of the cancer and continue with their future lives (Bernad, Zysnarska & Adamek, 2010; Lang et al., 2013).

It is suggested that the perceived availability, and provision, of social support may have protective effects on health and adjustment (House, Landis & Umverson, 1988). Evidence for the relationship between social support and cancer progression has been reported to be strong for breast cancer, but is "consistently unconvincing" for mixed cancer samples (Nausheen, Gidron, Peveler, & Moss-Morris, 2009). Reviewing the existing literature, Usta (2012) concludes that there is evidence supporting the existence of beneficial effects of emotional support from family members on physical and psychological adjustment to cancer. In HNC patients, Katz et al. (2003) report that social support may have a buffering effect on wellbeing for females but not males, therefore social support may facilitate adjustment to HNC differently in males and females. However, Deno et al. (2012) report that the literature exploring the relationship between social support and adjustment to HNC is inconsistent. Currently, the nature of the association between social support and adjustment to cancer, and the mechanisms

involved are not well understood. The investigation and understanding of these would be particularly beneficial for HNC patients since they often have increased difficulties in social and physical functioning following treatment.

In addition, it has been highlighted that there are barriers to accessing social support. Bernad et al. (2010) discuss some reasons why cancer patients may not access social support, including fear of developing dependence on others, fear of others' lack of understanding of their difficulties, and a lack of skills in asking for support. These barriers were also found in our study, most notably fear of others' lack of understanding (discussed as others' expectations to be 'alright') and lack of skills and experience in asking for support. Participants in the current study also discussed their reluctance to ask for support as they wished to remain independent. Further exploration into the barriers to accessing social support would also be beneficial as a greater understanding of these would then open opportunity for these to be overcome so that patients may feel more able to access the support they require.

There is also now increasing attention being paid to the effects of cancer on families and family caregivers since it has the potential to change family dynamics and place increased demands on family members (Balfe, Keohane, O'Brien & Sharp, 2017; Nightingale et al., 2016; Veach, Nicholas & Barton, 2002; Watson & Boulton, 2015). Veach et al. (2002) discuss how the dynamics and structure of a family may change over the course of cancer trajectory, and the importance of the family system remaining organised and stable to maintain family functioning, but also to be flexible enough to adapt to the different demands encompassed within the varying phases of cancer (e.g. diagnosis, treatment, survivorship). This may place increased demand on family members who may need to fulfil the role of the cancer patient as well as providing care for them and managing their own emotional reactions to cancer (Veach et al., 2002; Watson & Boulton, 2015). Emotional support has been reported to be the most frequently provided support by family caregivers, with one third of HNC patients rating this provision of support and care to be "a considerable burden" to their family member (Precious, Haran, Lowe & Rogers, 2012). Nightingale et al. (2016) reported that most family caregivers were interested in participating in wellness programs designed to support them, though time pressures and care provision for their loved one were potential barriers to engagement. Additionally, Balfe et al. (2017) explored the support

needs and barriers to accessing this within HNC family caregivers. They identified that carers often ‘impression manage’; hiding their emotions and struggles from others (especially the HNC patient), and that although carers have a desire to talk, others’ reactions to cancer and expectations of carers can be problematic and preclude this open dialogue. Some of these issues are mirrored in the results of our study, and there is an increasing recognition that caregivers and families require support when their family member is diagnosed with HNC.

4.3 Making a Choice to Change

‘Making a choice’ indicates some critical moment in which a shift is made to cognitive, and subsequently, behavioural action. This may be understood as reaching a ‘readiness for change’, described as part of the transtheoretical model of change which includes a systematic change in an individual’s readiness to consider and adopt a new behaviour (Prochaska & DiClemente, 1982, 1983). Specifically, the ‘making a choice’ stage of the proposed adjustment model may be conceptualised as transitioning into the contemplation and preparation stages proposed by the transtheoretical model, in which the patient may start to become aware that there is a problem, and intend to take action to address this. It is generally accepted that there are distinct stages of change, however, there is a paucity of literature investigating the transition between these change stages. Prochaska and DiClemente (1982) suggest ten processes of change which may facilitate movement between stages, however, little research has investigated these. A handful of studies have attempted to identify factors associated with different stages which may influence readiness to change (Conner-Spady et al., 2014; Schüz, Sniehotta, Mallach, Wiedemann & Schwarzer, 2009).

Hedeker, Mermelstein and Weeks (1999) suggested that a threshold model may account for transitions between stages. In their study with skin cancer patients, they identified two thresholds; contemplation threshold (between precontemplation and contemplation), and action threshold (between contemplation and action). They reported that worry influences the contemplation threshold such that at a certain intensity it may facilitate an individual in precontemplation stage to enter the contemplation stage, and that self-efficacy influences the action threshold. A similar concept of reaching a threshold was also included within Conner-Spady et al’s (2014) study which

qualitatively investigated the factors patients consider when assessing their readiness for joint replacement surgery. Within this study, participants described needing to feel mentally ready (described as an internal state) and physically ready for surgery. Encompassed within feeling mentally ready, participants discussed their experience of pain and that feeling they had ‘no choice’ because all alternative solutions were ineffective was a motivator for change (i.e. surgery). The impact of pain on their social life and independence, and feeling as though they wanted to regain control of their lives were also motivators for change. These motivating factors may be considered to have reached a ‘threshold’ in which they then facilitated readiness for change. In the current study similar principles may have influenced participants reaching the point of ‘making a choice’, for example they may have reached a threshold of feeling low and unhappy with their situation and subsequently contemplated change.

Furthering the suggestions made above that self-efficacy is important for behavioural change, Schüz et al. (2009) suggest that coping planning and self-efficacy predict transition from intention to action. They identified that in individuals targeted with a programme aimed at improving oral hygiene differences in self-efficacy supported the differences between those who only intended to change and those who had already started to enact changes. Therefore, belief about their ability to make changes may be important for arriving at ‘making a choice’ and may be an appropriate target for psychological intervention. Furthermore, Schüz et al. (2009) also reported that action planning was predictive of a transition between precontemplation and contemplation of change. Resulting from these findings the authors suggest that individuals who have not yet formed explicit intentions to change may benefit from ‘if-then’ planning. This type of planning has previously been reported by Armitage (2006) as helpful in promoting progression in precontemplation and contemplation stages when considering dietary changes. Applied to the current study, it is possible that participants engaged in this type of planning spontaneously as part of deciding what they want for themselves, for example, “*if* I continue to avoid socialising and engaging in activities, *then* I will stay unhappy” or “*if* I seek help and approach my frustrations differently *then* I will be happier with the person that I am”. However, these studies have been conducted with a variety of client groups and suggestions regarding how these may be applicable to HNC patients is speculative and would require further research.

As highlighted above, where patients may be continuing to struggle against the changes brought about by HNC, it may be helpful to consider the Transtheoretical Model, establishing which stage a patient may be at, and tailoring interventions to increase motivation to adopt alternative behaviours/approaches to fit with their readiness to change. Motivational interviewing has been demonstrated to positively impact upon individuals' readiness to change, helping them to engage more effectively with psychological interventions (Rubak, Sandboek, Lauritzen & Christensen , 2005; Westra & Dozois, 2006).

4.4 Acceptance vs Adjustment

As stated in the journal paper the concept of 'accepting' changes and challenges resulting from HNC has been discussed in numerous other qualitative studies (Costa et al., 2014; Ganzer et al., 2015; Henry et al., 2014; Semple et al., 2008). Semple et al. (2008) discuss that 'acceptance' of physical changes in HNC patients was facilitated by their understanding that surgery was the only/most successful way of curing cancer (analogous to my "no alternative" findings). Within this study, coping also included an element of "stoic acceptance" in which patients "accept what it is" and have an attitude of "it has happened so have to deal with it" (Semple et al., 2008). Costa et al. (2014) described an acceptance and resignation to the presence of cancer.

Within some studies, acceptance is conceptualised as an alternative to denial, which views it as a passive process. The definition and process of acceptance within ACT is at odds with some of the definitions and processes provided within the current study and other qualitative studies since it asserts that acceptance as an active process: *"the voluntary adoption of an intentionally open, receptive, flexible, and non-judgmental posture with respect to moment-to-moment experience. Acceptance is supported by a 'willingness' to make contact with distressing private experiences or situation, events, or interactions that will likely trigger them"* (Hayes et al. 2011, p. 272).

However, the current study was not in a position to fully explore the meaning that participants assigned to 'acceptance' and therefore there is currently limited insight into how HNC patients may engage in, and use the term acceptance. Some participants in the

current study suggested that they came to ‘accept’ their HNC and its related struggles as they perceived that there was no alternative. The origin of this conclusion is important for the understanding of how patients use the term acceptance. If this ‘no alternative’ acceptance arose from a choice to stop the fight against their struggles, and simply allowing their difficult experiences to occur, it may be considered ‘acceptance’ as ACT defines it. However, if this ‘acceptance’ arises from a place of hopelessness, then it would not be considered acceptance as ACT would suggest. Further research using alternative methodology (e.g. IPA) is necessary to explore the meanings assigned to ‘acceptance’ by HNC patients.

There may be some theoretical overlaps between acceptance and adjustment. In a study investigating how patients respond psychosocially to prostate cancer, the authors equate acceptance with adjustment, stating that high scores on the Acceptance of Illness Scale (AIS) indicate that the patient has adjusted well to the presence of cancer (Czerw, Religioni, Deptata, & Fronczak, 2017). The AIS aims to examine the extent to which a patient is able to ‘accept’ the illness without experiencing negative emotions or reactions. Eight statements relating to the negative consequences of ill health (including physical limitations, dependence on others, and lowered self-esteem) are rated between ‘1’ strongly agree and ‘5’ strongly disagree (Czerw, Bilinska & Deptala, 2016). However, this equivalence between acceptance and adjustment views adjustment as an outcome associated with decreased emotional reactions and distress, rather than a process as it has been conceptualised within the current study. The active process conceptualisation of acceptance described above offers a theoretical perspective regarding how patients may engage in some adjustment to cancer. However, the adjustment process involving changes which allow an individual to integrate cancer into their life whilst maintaining some normality is broader than simply responding to their experiences with an openness and willingness to allow space for difficult experiences. Adjustment also includes elements of making practical and cognitive changes with respect to approaching problems differently. Furthermore, Nicholas and Asghari (2006) investigated the role of pain acceptance in accounting for adjustment to chronic pain and reported that engagement in activities despite pain, and a willingness to accept pain did not sufficiently explain the process of adjustment to pain (conceptualised as a combination of depression severity, pain intensity, and physical disability).

4.5 Coping strategies

Previous literature has identified several coping strategies which have been described as beneficial in patients with HNC. Within the current study, participants described how they put things into perspective by considering that others are worse off, and that their physical limitations, disfigurements, and other changes (e.g. difficulties in eating) are effects which may be endured in return for being alive. They stated that being alive was the most important thing, which made these effects more bearable. Other studies also described this attitude; that facial disfigurement and challenges with eating are the ‘price to be paid’ for not having cancer (Costa et al., 2014; Ganzer et al., 2015; Semple et al., 2008). Costa et al. (2014) also reported on HNC patients’ determination to face life with optimism despite the distress that they may experience in relation to their facial disfigurement. They cited a gratefulness for survival as a motivating factor for this optimism, which was also observed in the current study. Participants reflected on how difficult they found dealing with facial disfigurement, often describing it as an initially traumatic experience when they first saw their disfigurement, but that their gratitude to the medical professionals who had ‘saved their lives’ helped to diminish these feelings over time. This satisfaction with ‘mere survival’ and reappraisal of life was also discussed by Semple et al. (2008).

Semple et al. (2008) also described that their participants spontaneously engaged in early graded exposure in order to gain confidence for social functioning. This was discussed by some of the participants in the current study. Some participants explained that they had made themselves socialise with others in order to subsequently gain confidence, and some described that they were awaiting a return of confidence before they started to re-engage in the social world. This has implications for psychological interventions which may aim to increase patients’ social confidence and functioning, therefore, further research into this coping strategy would be beneficial.

Religion and spirituality have also been discussed within other studies, and was cited as an important coping factor (Costa et al., 2014). However, these topics did not emerge in the present study. Within the sharing of the model, one participant described that she thanks her “guardian angels” for looking over her, though this appeared to be an isolated element as she did not describe herself as particularly spiritual or religious. In future studies, if this element were incorporated into early interview schedules,

contrasting results may be found in which religion and spirituality may play an important role in adjusting to HNC.

4.6 Proposed Model and its Relation to Existing Cancer Adjustment Models

Critique levelled at existing cancer adjustment models included the point that the models largely focused on cognitive rather than emotional processes, however, this criticism may also be applicable to my proposed model. Many processes included in the proposed model, for example, acceptance, making changes (to outlook/like focus), and putting things into perspective are predominantly cognitive in nature. During analysis of the data in the present study, it became apparent that since processes need to be verbalised in order to be explored within interviews, it is likely that these processes will appear to be dominated by cognition. It can be difficult to convey emotional processes verbally, whereas cognitive processes are inherently language-based, therefore it is understandable that adjustment models may be predominantly cognitive in nature. Although I endeavoured to include emotional and social components within the current model, this may also be open to critique.

The proposed model has some commonalities and differences with existing cancer adjustment models. The Social-Cognitive Transition (SCT) model of adjustment (Brennan, 2001) somewhat neglects the role of the social world and the Model of Restorative Wellbeing (Hoffman et al., 2013; Lent, 2007) considers how environmental support (social support) may facilitate adjustment, but it does not consider any adverse effects of this. My proposed model does consider the social context of the patient, both in terms of how it may hinder adjustment (others' expectations as barriers to progress) or help adjustment (talking with others). The negative consequences of cancer, as described by Moorey and Greer (2002, 2011) were salient within the current findings; change in mental and physical abilities, change in personal and social role, and change in appearance. Within the Cognitive Model of Adjustment (Moorey & Greer, 2002, 2011), emotions are considered to be consequential of cognitive appraisal of threat though are not considered much beyond this. The proposed model, as in the SCT model, does not specify how emotions arise, however, it does consider how patients may utilise different strategies and processes in order to manage and cope with them.

Other aspects of the proposed model may also be perceived to be similar to existing models. The ‘life domain adjustment’ contained within the Model of Restorative Wellbeing (Hoffman et al., 2013; Lent, 2007), which encompasses engaging in goal-directed activity, may be seen to be similar to the ‘making changes’ and ‘redefining and regaining normality’ processes in the proposed model. Furthermore, the Model of Restorative Wellbeing suggests that the ‘life domain adjustment’ leads to improved life satisfaction, which is contained within the regaining normality process of the current model. Within the Model of Restorative Wellbeing, Hoffman et al. (2013) acknowledge that following cancer, there may be a need for a new baseline since it may not be possible for patients to return to their previous level of functioning – this mirrors ‘redefining normality’. The proposed model, however, differs in how it conceptualises the cancer experience. In both the Model of Restorative Wellbeing (Hoffman et al., 2013; Lent, 2007) and the Cognitive Model of Adjustment (Moorey & Greer, 2002, 2011), the cancer diagnosis and experience is conceptualised as a single problematic event. The Cognitive Model of Adjustment focuses on the perceived threat of survival, however, my findings suggested that this may not be a central focus in later stages of adjustment since this is often diminished (participants had received ‘the all clear’) but adjustment is still ongoing. The proposed model offers flexibility in how HNC effects are ongoing and fluctuating, and how adjustment may respond to this.

A final convergence of models is worth noting; in the proposed model and existing models, the salient experiences of adjustment are less about site-specificity and more about the processes individuals engage in to adjust to the changes. As stated in the journal paper, the processes described within the proposed model do not appear to be specific to HNC, despite the various specific experiences and physical sequelae. Although the proposed model is mapped on to the cancer trajectory and some aspects requiring adjustment may be as a direct result of HNC or its treatment, the processes involved may be just as applicable to other cancer types and chronic illness, as is true for existing cancer adjustment models. Although the findings of this study did not identify a unique process of adjustment to HNC, arriving at commonalities with other cancer adjustment models through an inductive, grounded approach adds strength to the existing (and proposed) models and the value of this bottom-up approach.

4.7 Study Strengths and Limitations

4.7.1 Strengths

The study aimed to generate an adjustment theory grounded in participant data. The data was collected from diverse sources, including participants who had and had not received psychological input as a result of their HNC experiences, and ranged from one-week post-diagnosis (had not yet received treatment) to nine years post-diagnosis and treatment. This diversity provided opportunity to identify and examine negative cases, resulting in a flexible model which may account for a variety of experiences. The findings also provide implications for clinical practice and future research.

Throughout the interview and analysis process, I endeavoured to remain as close to the data as possible. Within interviews, I reflected back my understanding of participants' accounts of their experiences to ensure the validity of my understanding, and offered hypothetical relationships between aspects of their experience. The generated model was also shared with the final three participants, inviting them to confirm or refute the processes hypothesised and the links between them, to further enhance the validity of my findings.

A further strength of the study was the use of, and adherence to, quality criteria (outlined in section 2.8 of this paper) to enhance the credibility of my findings (see Appendix 18 for further details about how these criteria were met). I utilised supervision to maintain reflexivity and monitor my influence over the results. Additionally, audit trails (for example use of memos) regarding the development of categories, concepts, and theory development were routinely kept (see Appendix 16 for an example memo discussing the development of the core category).

4.7.2 Limitations

As stated in the journal paper, several limitations may be identified regarding our sample and recruitment. Firstly, the sample included within the study is small, relative to the number of people with HNC diagnoses. Furthermore, the heterogeneity within our small sample was large, consequently the possibility of shared experiences may be limited. However, the aim of this study was to generate a mid-level theory, thus heterogeneity was helpful. Furthermore, the concepts within the model were deemed to

have reached sufficiency, therefore, the heterogeneity does not appear to have adversely impacted upon the study's results.

Secondly, there was an inherent gate-keeping process that occurred before potential participants were approached to participate in the study. Therefore, although the current model broadly fits with my participants, it may not fit others, who, for various reasons were not approached to participate in the study; they may fundamentally think differently. This particularly relates to patients with terminal diagnoses. Furthermore, all participants were of a similar ethnicity and therefore the impact of cultural factors on a process of adjustment to HNC is likely to be missing from the current model.

Thirdly, since participants self-selected (once made aware of the study), there may have been additional shared characteristics between participants that may not be shared by those who did not wish to be involved with the study. One such characteristic was identified within the present participants as they all reported that they had consented to the study to contribute to work that may have the potential to help others in their position. Although this factor was consistent across all participants, other factors such as time since diagnosis, perceived stage of adjustment and psychological distress, and support networks differed substantially between participants.

Although it is also acknowledged that adjustment is an ongoing process, data was collected retrospectively; therefore, patients' accounts (years later) may not be accurate reflections of their experiences. For some participants, the period since diagnosis and treatment completion was up to nine years, and within the interview it was stated that they struggled to remember aspects of their experience. Furthermore, their current thoughts and feelings may impact on how they recall and discuss their adjustment experiences.

4.8 Further Clinical Implications and Relevance for Clinical Psychology

As stated in the journal paper, my model may be useful for informing psychological intervention which may aim to facilitate psychological adjustment. The use of the model in psychological interventions would enable clinical psychologists to consider the processes that patients have engaged in, and which may be beneficial to target within

intervention. This focus on process is also beneficial since Hulbert-Williams et al. (2015) suggest that simply looking at outcomes is insufficient for establishing whether interventions may be useful, and instead advocate for attention to be paid to the psychological processes of change. With this in mind, it is reasonable to consider that ACT may provide a good fit for facilitating adjustment to HNC. The change process in ACT includes engaging in processes and strategies which may allow an individual to change their relationship with negative thoughts and emotions, rather than attempting to directly change the thoughts and emotions themselves (Fashler et al., 2018). This concept of the change processes involved in ACT is comparable to the core category of 'modifying your relationship to the changes cancer brings' contained in the proposed model. Furthermore, ACT offers a holistic intervention, rather than being symptom-based (Hulbert-Williams et al., 2015), which fits with the requirements discussed in the journal paper.

In addition to informing psychological interventions, the model may also be a useful information source to be provided directly to HNC patients in the form of a booklet or information leaflet. Providing the information to HNC patients in this way may help to normalise some of their difficult experiences when they are unexpected. For example, other studies have discussed how HNC patients may experience seeing their facial disfigurements for the first time as traumatic and frightening and subsequently need considerable emotional support following this (Henry et al., 2014). Similarly, Roing et al. (2009) highlighted the impact of living with 'invisible' disfigurements (e.g. dry mouth) and how oral cancer patients struggled to adjust to their new way of "being" in the world without seeking professional help. The provision of this information in this format may serve as the initial step into understanding a potential process of adjustment, and the emotional experiences that they may encounter. A leaflet/booklet may also function as an aid to other HNC professionals, facilitating their conversations with patients regarding potential psychological difficulties and adjustment to HNC. The provision of written information also attends to some of the information needs of HNC patients; written information may help to consolidate information and discussions, and patients may refer back to it when they feel more able to process it.

4.9 Further Implications for Future Research

My study highlighted that the provision of information to HNC patients plays a central role in developing their own understanding. This understanding subsequently facilitates acceptance and enables patients to make important changes. Information needs of HNC patients have been highlighted in several studies to be a particularly challenging area. For example, Costa et al. (2014) discuss how a lack of information and knowledge may result in high stress levels for HNC patients, and Semple et al. (2008) discuss the beneficial effects of having an ‘expert patient’ to help patients to overcome their post-treatment challenges. At present, most information-giving literature for HNC focuses on initial treatment options and does not attend to the information required for subsequent recovery and adjustment. A review into the information needs of HNC patients reported that patients may have a preference for overall information to be provided, rather than being provided incrementally, and in a truthful and compassionate manner (Ziegler et al., 2004). In guidelines to clinicians, Humphris (2016) suggests that “timely” information is provided in addition to “brief supportive advice”. However, the current study highlights the difficulties in achieving this and striking the balance between providing helpful, accurate, and timely information against providing too much information such that it is forgotten or distressing to the patient. The information needs of HNC patients must be considered and explored further as they may be fundamental to lessening distress (Costa et al., 2014) and facilitating patients’ meaning- and sense-making processes (Lang et al., 2013). It would be pertinent for future research to explore the provision of information regarding access to psychological assistance, and recovery aspects rather than focusing purely on treatment options.

Arising from the involvement of family members providing support to HNC patients, there is also a need for further research into the impact on family members/carers. These individuals are often heavily involved in providing support and taking over roles when patients cannot fulfil them. Understanding the impact will help to support family members/carers so they may continue to support their loved one. Several participants in the current study also emphasised how much the diagnosis, illness, and effects of treatment had affected their loved ones since it may also be experienced as a traumatic event for family members. Issues of loss may also be present for family members, for example the potential loss of family aspects/identity (e.g. eating out), and loss of the role that their loved one may have fulfilled for them.

Owing to the contrasting views and descriptions of ‘acceptance’ within the current study, this may be a helpful focus of future research. ACT suggests that ‘acceptance’ is part of a change process which facilitates psychological flexibility, thus freeing the individual from their unhelpful relationship with their cognitive and behavioural processes (Hayes et al., 2011). This psychological flexibility is then hypothesised to allow individuals to act in accordance with their values, thereby alleviating their distress. Within ACT ‘acceptance’ is a process which is understood to be a willingness to allow distressing emotions and thoughts; making space for them (Harris, 2009). It is explicitly stated that acceptance is not a tolerance or resignation. Resulting from this definition, ‘acceptance’ in the form described by participants in the current study would not be considered to foster psychological flexibility. Nevertheless, patients’ definition and process of ‘acceptance’, which includes elements of resignation, appear to be facilitative of their psychological adjustment to HNC. Therefore, it would be beneficial to investigate mechanisms of change associated with ‘acceptance’, to establish how this effect occurs.

Future research into the adjustment process could also use a longitudinal design which may aim to explore how engagement in adjustment processes changes over time. The current study demonstrated that it was possible to recruit participants up to one week post-diagnosis, therefore longitudinal studies may be possible. It may also be beneficial for future longitudinal research to explore *how* patients transition between the processes identified within the proposed model; what specific factors, circumstances, or internal states may facilitate a patient to continue along to the next process in the adjustment trajectory.

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6 Appendices

Appendix 1: Journal Author Guidelines

Author Guidelines for European Journal of Cancer Care. Only relevant guidelines are provided, please see [http://onlinelibrary.wiley.com/journal/10.1111/\(ISSN\)1365-2354/homepage/ForAuthors.html](http://onlinelibrary.wiley.com/journal/10.1111/(ISSN)1365-2354/homepage/ForAuthors.html) for full details.

Author Guidelines

Manuscript Types

The European Journal of Cancer Care publishes original research reports, literature reviews, guest editorials, letters to the Editor and special features on current issues affecting the care of cancer patients.

The Journal does not publish case reports, case studies, or short communications, and these will be rejected without review if submitted.

Manuscript Style

Manuscripts should usually be between 3,000 and 8,000 words in length, excluding references, figures, and tables. The manuscripts must contain:

Title page: This should contain a concise, descriptive title of the article, the names and qualifications of all authors, their job titles, affiliations and full mailing address, including email addresses and fax/telephone numbers. The title page must also contain details of any source(s) of support in the form of grants, bursaries, free use of equipment, drugs or any other benefits which should be disclosed. The e-mail address of a corresponding author must be provided for correspondence purposes and the Editorial Office alerted of any changes to this if necessary.

Abstract: This should be written as a single paragraph of no more than 200 words. It should not contain subheadings and should be on a separate page. Where appropriate, authors should ensure that the abstract describes the purpose, population, methodology, sample, setting and details of the variables under study. It should also highlight the outcome measures and main conclusions of the study. The abstract should accurately reflect the title and should be followed by no more than six keywords (see below).

Main Text: This should begin on a separate page, and include an introduction, methods, results, and a discussion section. Reviews must contain a clear exposition of the search strategy, databases, keywords and any selection/evaluation criteria used in the review where appropriate. Authors should avoid using abbreviations, acronyms and footnotes. The use of non-discriminatory language is encouraged and spelling should conform with that used in the Concise Oxford Dictionary of Current English by setting any spell checker used to UK English (not US English). Manuscripts must clearly specify that ethical approval has been obtained for the study where required.

References

List all sources in the reference list alphabetically by name. In text citations should follow the author-date method. This means that the author's last name and the year of publication for the source should appear in the text (see sample citations below) and a complete reference should appear in the reference list at the end of the paper. (*Samples are provided*).

References are styled according to the sixth edition of the Publication Manual of the American Psychological Association (APA). A sample of the most common entries in reference lists appears below. Please note that for journal articles, issue numbers are not included unless each issue in the volume begins with page one. References should refer only to material listed within the text.

Tables: Should include only essential data. Each table must be typewritten on a separate sheet and should include a clear title. Tables should be numbered in the same way as figures and listed on a separate page at the back of the manuscript.

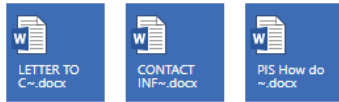
Titles, Keywords and Discoverability

The Journal places great weight upon the electronic discoverability of its papers. Manuscript titles and keywords should therefore, accurately portray the scope of the paper and include words pertaining to the population or sample, the method of inquiry, any tools or measures used and its key findings as appropriate. These words should be reiterated at least once in the abstract. Titles should be clear, descriptive, and avoid the use of metaphor, elaborate language or respondent quotations which are less likely to be discovered by the electronic algorithms of modern search engines.

Appendix 2: Example Email to Clinicians

To: GRIFFIN, Matthew (NOTTINGHAM UNIVERSITY HOSPITALS NHS TRUST); CHRISTIAN, Judith (NOTTINGHAM UNIVERSITY HOSPITALS NHS TRUST);
Cc: msxlkc@exmail.nottingham.ac.uk;

📎 3 attachments



[Download all](#)

Dear Dr Griffin and Dr Christian,

I met with you a while ago to discuss recruitment for my research project as part of my DClinPsy thesis and you both kindly agreed to recruit for me.

I wanted to let you know that I am now in a position to start recruiting as I have received all of my approvals (REC & HRA) and Nottingham University Hospitals have confirmed capacity and capability to support this research. I have attached the participant information sheet, and letter to clinicians so that you may be able to start to approach patients/consider who may be appropriate to approach about participation in this study. I have also attached a contact information form if potential participants would prefer to complete this so that I make first contact with them.

I wondered if it would be helpful for me to meet with you at all to discuss this? I have cc'd my university email address into this email as I have better access to this account.

Many thanks

Louise Calver
Trainee Clinical Psychologist

Appendix 3: Letter to Clinicians

Louise Calver
Division of Psychiatry & Applied Psychology
University of Nottingham
YANG Fujia Building, B Floor
Jubilee Campus
Wollaton Road
Nottingham NG8 1BB
msxlkc@nottingham.ac.uk

Dear Clinician,

My name is Louise Calver and I am a Trainee Clinical Psychologist on the Trent DClinPsy programme. I am writing to you to request your assistance in recruitment for my doctoral thesis that is investigating the psychological adjustment to the experience of head and neck cancer.

As I am certain you are aware, there are many psychosocial challenges involved in an experience of head and neck cancer and its treatment. Individual experiences of head and neck cancer have been documented, however there is a gap in the literature regarding adjustment to these experiences that provide a threat on an individual's functional integrity and appearance.

The purpose of my study is to develop a psychological understanding and theory of adjustment to head and neck cancer, including both visible and functional changes. This model will potentially provide a framework for Clinical Psychologists to use within assessment, formulation and intervention; identifying areas for psychological work to be targeted in order to improve psychological well-being and reduce emotional distress. It is hoped that this study may provide a basis upon which further research can be developed in understanding and supporting individuals who have experienced head and neck cancer from a psychological standpoint.

The study will use qualitative design, using a semi-structured interviews with 6-15 participants who have experienced head and neck cancer. The interviews will be audio-recorded, transcribed and analysed using a grounded theory approach. Participants will be asked to take part in at least one 60 minute semi structured interview with the researcher, and will also be asked if they would consent to a further interview approximately 3-6 months later.

Participants that I am aiming to recruit will:

- Have an occurrence of head and neck cancer in the past or present.
- Be over 18 years old

- Be able to give informed consent
- *I would also ask that clinicians make a judgement about whether they would expect the potential participant to be in a stable condition or remission for a period of at least 12 months, and to only approach those patients who are likely to fulfil this criteria. This is because I am looking at the adjustment to living with head and neck cancer, and if this criteria is not fulfilled, it is possible that any adjustment process may well be in relation to end of life, rather than living with head and neck cancer and its effects, though I appreciate that this may not be the case for all patients.*
- The study can only include participants who speak English fluently as there would be difficulties with translation and would be likely that meaning and adjustment to such personal experiences may be lost in translation. Special requirements for individuals who may struggle to speak for an hour will be considered e.g. multiple shorter interviews.

There will be no exclusion criteria based on whether the participant has received treatment for the cancer since adjustment is a dynamic process and the present study is looking to incorporate the adjustment of the entire experience of head and neck cancer.

I have also included within this letter the information sheet that will be provided to participants should they express an interest in this study.

I am very grateful for the time you have taken to read this, and hope that my project is of interest to you and that you may be able to contribute to this by identifying and approaching patients on your caseload that fulfil the eligibility criteria.

If you have any further questions, please do not hesitate to contact me. I look forward to potentially working with you.

Yours Faithfully,

Louise Calver
Trainee Clinical Psychologist

Supervised by
 Dr Anna Tickle (Academic / Research Tutor and Clinical Psychologist) and Dr Nima Moghaddam (Research Tutor and Clinical Psychologist)

Appendix 4: Participant Information Sheet



Participant Information Sheet (Final version 1.1: 06.07.2017)

IRAS Project ID: 216710

Title of Study: How do patients adjust psychologically to the experience of head and neck cancer?

Name of Researcher(s): Louise Calver, Anna Tickle, Nima Moghaddam, Sanchia Biswas

We would like to invite you to take part in our research study. Before you decide whether you would like to be involved, we would like you to understand why the research is being done and what it would involve for you. Please read the following information carefully and discuss it with others if you wish. Please ask us if there is anything that is not clear or if you require further information.

What is the purpose of the study?

This study will explore the changes experienced by people who have been diagnosed and treated for head and neck cancer. The purpose of the research is to develop a theory about how people with head and neck cancer adjust to these changes. This will include consideration of their feelings, thoughts, coping style and potential changes in their adjustment over time.

Why have I been invited?

You are invited to take part because you are over 18 years old, have experienced head and neck cancer, and have expressed an interest about taking part in an interview to discuss any changes or challenges resulting from the cancer, and how you have adjusted to these.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. This would not affect your legal rights.

What will happen to me if I take part?

An interview will be arranged with you by Louise Calver (Trainee Clinical Psychologist). This can be at an NHS site, at the University of Nottingham, at your own home, or via telephone, depending upon your preference. Before the interview starts you can ask any questions before signing a consent form if you wish to be interviewed, this would need to be completed and emailed (or returned with pre-provided stamped address envelope) if

the interview is conducted via telephone. The interview will be approximately one hour in length and will be audio-recorded using a Dictaphone. You are free to ask to stop the recorder at any time if you want. If you need to take a break at any time, or wish to stop the interview, you can do so at any time without giving reason. The interview will be typed up electronically afterwards. We might want to interview you one more time, if you are willing. You can take part in just one interview. If you consent to a second interview, then you will be contacted approximately 3-6 months after your first interview via your preferred contact details to arrange this.

You will also be asked to complete a personal details form which will ask for some personal information about you, for example, employment status and details about your cancer.

Following interviews it is expected that you will not be contacted until the results are available in September 2018.

You will be free to refuse to answer any question, without giving any explanation, and can leave or terminate the interview at any time.

Expenses and payments

You will not be paid to take part, though travel expenses will be available to cover your costs of travelling to the interview if necessary.

What are the possible disadvantages and risks of taking part?

We do not anticipate any risks associated with taking part in this study. We do recognise that being diagnosed and treated for head and neck cancer may have been distressing, and that talking about it may be upsetting for you. The interviews will be conducted by Louise Calver who is sensitive to this fact and will support you within the interview if you do feel distressed. If you need to take a break in the interview or wish to end it, you can do so at any time. Information about possible support will also be provided.

What are the possible benefits of taking part?

Taking part in the interview may give you a chance to reflect upon your experiences. This information may help us to understand how people cope with the experience of head and neck cancer, and its potential challenges. Findings from this study are intended to help other people who are going through similar experiences and to help inform psychological assessments and interventions.

What happens when the research study stops?

Once the study has finished, you will be contacted with the results if you have given consent and contact details for this.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. The researchers contact

details are given at the end of this information sheet. If you remain unhappy and wish to complain formally, you can do this by contacting NHS Patients Advice and Liaison Service (PALS) on 0800 183 0204 (QMC/Nottingham City Hospital), 01623 672366 (King's Mill Hospital, Sherwood Forest Hospitals NHS Foundation Trust) or 0800 783 7691 (Royal Derby Hospital).

Will my taking part in the study be kept confidential?

We will follow ethical and legal practice and all information about you will be handled in confidence.

If you take part, some parts of the data collected for the study will be looked at by authorised persons from the University of Nottingham who are organising the research, and by transcription services who will have signed a confidentiality agreement. The data may also be looked at by authorised people to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

All information which is collected about you during the course of the research will be kept **strictly confidential**, stored in a secure and locked office, and on a password protected database. Any information about you which leaves the hospital will have your name and address removed (anonymised) and a unique code will be used so that you cannot be recognised from it. Quotes from your interview may be used in the final report of the research, but these will be given a different name to yours and will not include any other information that may identify you.

Your personal data (address, telephone number) will be kept for 6-12 months after the end of the study so that we are able to contact you about the findings of the study (unless you advise us that you do not wish to be contacted). All research data, for example interview transcripts, will be kept securely for 7 years. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team will have access to your personal data.

Although what you say in the interview is confidential, should you disclose anything to us which we think indicates that you or anyone else is at any risk of harm or criminal activity, we may feel it necessary to report this to the appropriate agencies. Wherever possible, we would talk to you about this before telling others.

What will happen if I don't want to carry on with the study?

Your participation is voluntary and you are free to withdraw at any time, or decline to answer any question, without giving any reason, and without your medical care or legal rights being affected. You can request for your information to be destroyed up to seven days following your interview, after this time the information collected so far cannot be erased and that this information may still be used in the project analysis.

Involvement of the General Practitioner/Family doctor (GP)

Your GP will not be informed about your involvement in this study.

What will happen to the results of the research study?

The results of this study will be written up to fulfil the research requirements of a Doctorate in Clinical Psychology. The results will also be submitted to a peer-reviewed journal in order to share these results to a wider group. An information leaflet for patients will also be developed to be available within the participating NHS sites. It is anticipated that these will be completed and ready for submission by September 2018. If you wish to have a copy of the results please say this at your interview, or alternatively contact the researcher on the contact details below.

Who is organising and funding the research?

This research is being organised and funded by the University of Nottingham.

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by East Midlands – Nottingham Research Ethics Committee.

Further information and contact details

If you would like to participate in this research, please contact me (Louise Calver) using the details below to let me know if you would like to attend a face-to-face, or telephone, interview, and what days/times may be most convenient for you.

Louise Calver
Division of Psychiatry & Applied Psychology
University of Nottingham
YANG Fujia Building, B Floor
Jubilee Campus
Wollaton Road
Nottingham NG8 1BB

msxlkc@nottingham.ac.uk

Appendix 5: Contact Details Form



Contact Information Form (Final version 1.0: 18.05.2017)

Title of Study: How do patients adjust psychologically to the experience of head and neck cancer?

IRAS Project ID: 216710

Name of Researcher: Louise Calver

Name of Participant:

Preferred contact details for arranging interview:

Preferred contact details for receiving study results and summary (if applicable):

☐

Address

☐

Email Address

Appendix 6: Consent Form

CONSENT FORM **(Final version 1.0: 18.05.2017)**

Title of Study: How do patients adjust psychologically to the experience of head and neck cancer?

IRAS Project ID: 216710

Name of Researcher: Louise Calver

Name of Participant:

Please initial box

1. I confirm that I have read and understand the information sheet version number 1.1 dated 06.07.2017 for the above study and have had the opportunity to ask questions.

☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, or decline to answer any question, without giving any reason, and without my medical care or legal rights being affected. I understand that I can request for my information to be destroyed up to seven days following my interview, after this time the information collected so far cannot be erased and that this information may still be used in the project analysis.

☐

3. I understand that data collected in the study may be looked at by authorised individuals from the University of Nottingham, the research group and regulatory authorities where it is relevant to my taking part in this study. I give permission for these individuals to have access to these records and to collect, store, analyse and publish information obtained from my participation in this study. I understand that my personal details will be kept confidential.

☐

4. I understand that the interview will be audio recorded and transcribed either by the researcher or external transcriber (following a confidentiality agreement) and that anonymous direct quotes from the interview may be used in the study reports.

☐

5. I agree to take part in the above study.

☐

A. I agree that the researcher may contact me following my interview to arrange a further interview.

☐

B. I wish to be contacted with the results of the study

☐

Name of Participant

Date

Signature

Name of Person taking consent

Date

Signature

Appendix 7: Debrief Sheet



Debrief Information (Final version 1.0: 06.07.2017)

Title of Study: How do patients adjust psychologically to the experience of head and neck cancer?

IRAS Project ID: 216710

Name of Researcher: Louise Calver

Thank you for taking part in this study!

Study Aim

This study aims to explore how people adjust to the changes that they may experience following diagnosis and treatment for head and neck cancer.

The purpose is to develop a theory about how people with head and neck cancer adjust to these changes. This will include consideration of their feelings, thoughts, coping style and potential changes in their adjustment over time.

Any Questions?

Do you have any questions or concerns about the interview, or the study?

Further Support

If you have been upset by anything that you have discussed within your interview, please contact any of the following people/services for support or advice:

- Your clinician (possibly your oncologist or psychologist)
- Your GP
- Samaritans on 116 123 (this number is free to call)
- You may also like to visit this website, which has a lot of helpful resources:

<http://www.sfh-tr.nhs.uk/index.php/clinical-psychology-cancer-service>

Complaints

If wish to make a formal complaint about this study, or an aspect of it, you can do this by contacting NHS Patients Advice and Liaison Service (PALS) on 0800 183 0204 (QMC/Nottingham City Hospital), 01623 672366 (King's Mill Hospital, Sherwood Forest Hospitals NHS Foundation Trust) or 0800 783 7691 (Royal Derby Hospital).

Withdrawing

Please remember that you have one week to withdraw your consent and have your data removed from the study. Doing so will not affect your treatment in any way. After this time your data will be included in the study. If you wish to withdraw, please contact me (Louise Calver) on:

msxlkc@nottingham.ac.uk

07930 989416

Appendix 8: Ethical Approval Documents

NHS Research Ethics Committee Approval Letter



Health Research Authority
East Midlands - Nottingham 1 Research Ethics Committee
The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

19 July 2017

Dr Thomas Schröder
Associate Professor in Clinical Psychology; Co-Director (Academic & Research)
University of Nottingham
Division of Psychiatry and Applied Psychology
University of Nottingham, YANG Fujia Building, B Floor
Wollaton Road, Nottingham
NG8 1BB

Dear Dr Schröder,

Study title:	How do patients adjust psychologically to the experience of head and neck cancer?
REC reference:	17/EM/0226
Protocol number:	17020
IRAS project ID:	216710

Thank you for your letter of 06 July 2017, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact hra.studyregistration@nhs.net outlining the reasons for your request.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

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

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

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

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

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

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

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

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

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

Ethical review of research sites

NHS sites

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

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [2016 To Whom it May Concern Liability]	1.0	23 May 2017
GP/consultant information sheets or letters [LETTER TO CLINICIANS How do patients adjust to head and neck cancer v1.0 date 18.05.2017]	1.0	18 May 2017
Interview schedules or topic guides for participants [INTERVIEW SCHEDULE How do patients adjust to head and neck cancer v1.0 date 18.05.2017]	1.0	18 May 2017
IRAS Application Form [IRAS_Form_17072017]		17 July 2017
Letter from sponsor [17020 SPONSOR LETTER How do patients adjust to head and neck cancer]	1.0	23 May 2017
Other [NGM CV How do patients adjust to head and neck cancer v1]	1.0	18 May 2017
Other [CONTACT INFORMATION FORM How do patients adjust to head and neck cancer v1.0 date 18.05.2017]	1.0	18 May 2017
Other [SCHEDULE OF EVENTS How do patients adjust to head and neck cancer v1.0 date 18.05.2017]	1.0	18 May 2017
Other [STATEMENT OF ACTIVITIES NON-INTERVENTIONAL How do patients adjust to head and neck cancer v1.0 date 18.05.2017]	1.0	18 May 2017
Other [DEMOGRAPHICS FORM How do patients adjust to head and neck cancer v1.1 date 06.07.2017]	1.1	06 July 2017
Other [DEBRIEF How do patients adjust to head and neck cancer v1.0 date 06.07.2017]	1.0	06 July 2017
Participant consent form [CONSENT FORM How do patients adjust to head and neck cancer v1.0 date 18.05.2017]	1.0	18 May 2017
Participant information sheet (PIS) [PIS How do patients adjust to head and neck cancer v1.1 date 06.07.2017]	1.1	06 July 2017
Research protocol or project proposal [PROTOCOL How do patients adjust to head and neck cancer v1.1 date 06.07.2017]	1.1	06 July 2017
Response to Request for Further Information		06 July 2017
Summary CV for Chief Investigator (CI) [TS CV How do patients adjust to head and neck cancer v1]	1.0	18 May 2017
Summary CV for student [LC CV How do patients adjust to head and neck cancer v1.0]	1.0	18 May 2017
Summary CV for supervisor (student research) [AT CV How do patients adjust to head and neck cancer v1]	1.0	18 May 2017

Statement of compliance

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

After ethical review

Reporting requirements

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

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

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

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:
<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

HRA Training

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

17/EM/0226

Please quote this number on all correspondence
--

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

Yours sincerely,



Mr John Aldridge
Chair

Email: NRESCcommittee.EastMidlands-Nottingham1@nhs.net

Enclosures: "*After ethical review – guidance for researchers*"

Health Research Authority Approval Letter



Health Research Authority

Dr Thomas Schröder
Associate Professor in Clinical Psychology; Co-Director
University of Nottingham
Division of Psychiatry and Applied Psychology
University of Nottingham, YANG Fujia Building, B Floor
Wollaton Road, Nottingham
NG8 1BB

Email: hra.approval@nhs.net

19 July 2017

Dear Dr Schröder,

Letter of HRA Approval

Study title:	How do patients adjust psychologically to the experience of head and neck cancer?
IRAS project ID:	216710
Protocol number:	17020
REC reference:	17/EM/0226
Sponsor	University of Nottingham

I am pleased to confirm that **HRA Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. Please read *Appendix B* carefully, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* – this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* – this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from www.hra.nhs.uk/hra-approval.

Appendices

The HRA Approval letter contains the following appendices:

- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

After HRA Approval

The document “*After Ethical Review – guidance for sponsors and investigators*”, issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

In addition to the guidance in the above, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the [HRA website](http://www.hra.nhs.uk), and emailed to hra.amendments@nhs.net.
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the [HRA website](http://www.hra.nhs.uk).

Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at <http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/>.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

IRAS project ID	216710
-----------------	--------

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>.

HRA Training

We are pleased to welcome researchers and research management staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

Your IRAS project ID is 216710. Please quote this on all correspondence.

Yours sincerely,

Steph Blacklock
Senior Assessor

Email: hra.approval@nhs.net

Copy to: *Ms Angela Shone, Sponsor Contact*
Teresa Grieve, Derby Hospitals NHS Foundation Trust, Lead R&D Contact

Derby Teaching Hospitals NHS Foundation Trust – Research and Development Capacity and Capability Approval

DHRD/2017/080. IRAS: 216710 - Confirmation of Participation

FK FROST, Kate (DERBY TEACHING HOSPITALS NHS FOUNDATION TRUST) <kate.frost@nhs.net>
Tue 29/08, 10:40
Calver Louise; Schroder Thomas; +1 more

Authorisations

You replied on 29/08/2017 14:32.

LoA - Calver L - issue... 248 KB
REC Approval 2017.0... 227 KB
SL45_(Approval)_Lett... 211 KB
Royal Derby Confirm... 605 KB
SOA_v1_19.07.17_216... 370 KB

Show all 5 attachments (2 MB) Download all Save all to OneDrive - The University of Nottingham

Action Items

Sent on Behalf of the DHFT Research Governance Team

Dear Dr Schroder and Louise,

Study Title:	How do patients adjust psychologically to the experience of head and neck cancer?
DHFT Study Reference:	DHRD/2017/080
IRAS ID:	216710
Chief Investigator:	Dr Thomas Schröder
Sponsor:	The University of Nottingham
Funder:	N/A

Louise - Please find attached your LoA that confirms your right of access to conduct research through Derby Teaching Hospitals NHS Foundation Trust for the purpose and terms and conditions detailed in the LoA.

Would you be able to forward this letter onto Graham Wilkes as notification of the LoA? The email address given on the NHS-NHS Performa form is bouncing back.

Further to the above study being issued with HRA/REC approval to receiving the LoA, this email confirms that Derby Teaching Hospitals NHS Foundation Trust (DHFT) has the capacity and capability to deliver the above study. You may now commence recruitment to this study subject to the terms of sponsorship and those detailed in this email and the HRA/REC approval letters.

- The agreed Recruitment Target for this Study: 8
- Recruitment end date: 30/09/2018
- The SoA acts as the site agreement for his study, please retain the fully executed version attached

Please supply the following information at the appropriate time points to dhft.randdadmin@nhs.net:

- The date of your first patient recruited to the study.
- Notification of any changes to the local study team, SUSARs, amendments, urgent safety measures or if the study is abandoned
- Notification of the actual end of recruitment date, end of participant follow up (if applicable), end of the study date and a copy of the end of study report.
- Details of any publications arising from this research project.

Please note that approval for this study is dependent on full compliance with all of the above conditions.

Also, please find below the list of HRA/REC, and R&D approved documents, for this study:

Document	Version	Date
GP/consultant information sheets or letters	1.0	18 May 2017
Demographics Form	1.0	06 July 2017
Debrief	1.0	06 July 2017
Participant information sheet	1.0	06 July 2017
Research protocol	1.0	06 July 2017

Please contact us using the contact details below if you require any further information.

Yours sincerely,
Kate Frost

Kate Frost
Clinical Trials Manager

Research and Development
Royal Derby Hospital | Room 5033 | University of Nottingham GEM School
Derby Teaching Hospitals NHS Foundation Trust
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Nottingham University Hospitals NHS Trust – Research and Innovation Capacity and Capability Approval

RE: IRAS 216710 Confirmation of Capacity and Capability at Nottingham University Hospitals NHS Trust

MS Michalak Stefan (Research & Innovation) <Stefan.Michalak@nuh.nhs.uk>
Yesterday, 15:29
Calver Louise ✓

Authorisations

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You replied on 21/09/2017 15:41.

Conditions of Confir... 251 KB
RSCH 795 PINK NHS ... 1 MB
NUH SOA 21.09.17.d... 93 KB

Show all 3 attachments (1 MB) Download all Save all to OneDrive - The University of Nottingham

Action Items

Dear Louise,

RE: IRAS 216710 Confirmation of Capacity and Capability at Nottingham University Hospitals NHS Trust

R&I Ref: 17ON065

Full Study Title: How do patients adjust psychologically to the experience of head and neck cancer?

Sponsoring Organisation: University of Nottingham

This email confirms that Nottingham University Hospitals NHS Trust has the capacity and capability to deliver the above referenced study. Please find attached our signed Statement of Activities as confirmation.

We agree to start this study on a date to be agreed when you as sponsor give the green light to begin.

Please be aware this confirmation of capacity is provided on the understanding and provision that you will follow the conditions set out in the attached document (NUH R&I of Confirmation of Capacity and Capability Conditions, v1).

If you wish to discuss further, please do not hesitate to contact me.

Kind regards
Nottingham University Hospitals NHS Trust

Dr Maria Koufali
Deputy Director Research and Innovation

Please note that the R&I department maintains a database containing study related information, and personal information about individual investigators e.g. name, address, contact details etc. This information will be managed according to the principles established in the Data Protection Act.

Sherwood Forest Hospitals NHS Foundation Trust – Research and Development Capacity and Capability Approval

IRAS 216710 - Confirmation of Capacity and Capability at Sherwood Forest Hospitals NHS Foundation Trust

D Donna Sowter - Research Assistant - SFH-KMH <Donna.Sowter@sfh-tr.nhs.uk> on behalf of David Hodgson - Consultant in Respiratory Medicine- SFH-KMH <David.Hodgson@sff>
Tue 22/08, 12:42
Schroder Thomas; Calver Louise; Lynne Allsop - Specialist Research Nurse Team Leader - SFH-KMH <Lynne.Allsop@sfh-tr.nhs.uk>; sfh-tr.researchandinnovation@nhs.net; +4 more ✓

Authorisations

You replied on 31/08/2017 14:54.

SOA_v1_19.07.17_216... 94 KB

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Action Items

Dear Dr Schroder

RE: Confirmation of Capacity and Capability at Sherwood Forest Hospitals NHS Foundation Trust.
Full Study Title: How do patients adjust to Head and Neck Cancer?

This email confirms that Sherwood Forest hospitals NHS Foundation Trust has the capacity and capability to deliver the above referenced study.

We agree to start this study on a date to be agreed when you give the green light to begin.

If you wish to discuss further, please do not hesitate to contact me.

Best wishes

Dr David Hodgson
Director of Research

Appendix 9: Good Clinical Practice Certificate

CERTIFICATE of ACHIEVEMENT

This is to certify that

Louise Calver

has completed the course

Introduction to Good Clinical Practice eLearning (Secondary
Care)

August 18, 2017

Modules completed:

Introduction to Research in the NHS
Good Clinical Practice and Standards in Research
Study Set Up and Responsibilities
The Process of Informed Consent
Data Collection and Documentation
Safety Reporting

This course is worth 4 CPD credits



National Institute for
Health Research
Clinical Research Network

Appendix 10: Transcriber Confidentiality Agreement



Data Protection Act 1998 Confidentiality Agreement for Transcribers

This Agreement is made as of 21/9/17 (Date), by and between the University of Lincoln, with principal offices at Brayford Pool Lincoln LN6 7TS (the University) and Helen Smith with principal offices at 21 Southfield Avenue, Syston, Leics, LE7 2LL (the Transcriber).

The Transcriber has been appointed by the University of Lincoln to transcribe audiotapes/audio files and documentation resulting from research undertaken by Louise Calver which will involve the disclosure to the Transcriber of personal data held by the University. Accordingly the Transcriber is required to deal with any such information in accordance with the terms of this Agreement and the Data Protection Act 1998.

The Transcriber undertakes to respect and preserve the confidentiality of personal data. Accordingly, for an indefinite period after the date of this Agreement the Contractor shall:

- maintain the personal data in strict confidence and shall not disclose any of the personal data to any third party;
- restrict access to employees, agents or sub-contractors who need such access for the purposes of the contract (and then only if the employee, agent or subcontractor is bound by conditions of confidentiality no less strict than those set out in this agreement, which the Transcriber shall enforce at the University's request);
- ensure that its employees, agents or sub-contractors are aware of and comply with the Data Protection Act 1998; and
- not authorise any sub-contractor to have access to the personal data without obtaining the University's prior written consent to the appointment of such sub-contractor and entering into a written agreement with the subcontractor including conditions of confidentiality no less strict than those set out in this agreement, which the Transcriber shall enforce at the University's request.

The Transcriber agrees to indemnify and keep indemnified and defend at its own expense the University against all costs, claims, damages or expenses incurred by the University or for which the University may become liable due to any failure by the Transcriber, its employees, agents or sub-contractors to comply with any of its obligations under this Agreement.

For the avoidance of doubt, the confidentiality imposed on the Transcriber by this Agreement shall continue in full force and effect after the expiry or termination of any contract to supply services.

The restrictions contained in this Agreement shall cease to apply to any information which may come into the public domain otherwise than through unauthorised disclosure by the Transcriber.

This Agreement shall be governed by and construed in accordance with the laws of England and the parties hereby submit to the exclusive jurisdiction of the English courts.

Signed for and on behalf of HELEN SMITH

Signed: Helen Smith Name: HELEN SMITH

Title: MISS Date: 21/9/2017

Signed for and on behalf of the University of Lincoln

Signed: J. Tompkins Name: JUDITH TOMPKINS

Title: SENIOR ADMINISTRATION/PA Date: 22.9.17

Appendix 11: Interview Schedules

First Interview Schedule

- What does the term 'adjustment' mean to you?
 - *When you hear the term 'adjustment', what comes to mind?*
 - *What is different now compared to before your diagnosis?*
 - *What changes have you noticed in yourself, if any? (Could prompt relationships, activities, emotions if struggle to answer. Could also prompt by asking them to compare a typical day before or after diagnosis). How did you notice these changes?*
- What adjustments have you made since your diagnosis, if any?
 - *In what way have you changed, if you have?*
 - *What adjustments have you made in the things that you do in day to day life? Did you expect these? Any surprised you?*
 - *What changes have you noticed in your relationships with others, if any?*
 - *What adjustments have others noticed in you, if any?*
 - *How would others see you now compared to before diagnosis?*
 - *What changes have you made to the roles that you take on?*
 - *Are there any ways in which the cancer has affected your life which you have not adjusted to? If so, please can you elaborate?*
 - *Are there ways in which you have changed the way you interact with people in any way? If so, please can you elaborate?*
 - *Are there ways in which you have changed the way you view the world/others? If so, please can you elaborate?*
- How did you know that you were adjusting (or had adjusted) to living with cancer? What did you notice?
 - *How did you come to realise this?*
 - *What thoughts/feelings do you have about the changes that you have made?*
 - *Upon reflection, are there any aspects of the adjustment process that particularly stand out for you?*
 - *If you don't think you have adjusted, do you think you need to make any adjustments? (If so) what would need to happen to start this process?*
- How did you cope with these adjustments?
 - *What did you do to aid the adjustment process, if anything at all?*
 - *What support did you receive to help you adjust to cancer? How did this help? If not, in what ways did it not help?*
 - *Is there anything that anyone has said or done that has been particularly helpful or unhelpful?*
 - *How do you plan to cope with the areas which you haven't adjusted to yet? (this is for ppts who might say they haven't fully adjusted to living with cancer yet)*
- What have been some of the challenges in making adjustments?
 - *How did you try to cope with them? Did this work?*
- Upon reflection, what does it feel like to know that you have adjusted to these changes we have talked about?
 - *How would you know you have reached this stage?*

- *How would you feel/behave/think?*
- *What would be different if you reach this stage?*
- *If you do not feel that you have reached this stage, how would you know when you have adjusted to the changes? What would this look like for you? What would you need to do for this to happen? What would you need others to do for this to happen?*
- Is there anything else that we have not mentioned that seems important to discuss?

General prompts:

- *Please tell me some more about that*
- *Please tell me what you're thinking about that question*
- *Can you give me an example if possible?*
- *What did you do/think when....happened?*

Second Interview Schedule

- What does the term 'adjustment' mean to you?
 - *When you hear the term 'adjustment', what comes to mind?*
 - *What changes have you noticed in yourself, if any?*
- When you first noticed something was wrong, how did you react?
 - *Were you expecting a cancer diagnosis?*
 - *How did you manage the diagnosis?*
 - *Did anything help you to start to cope with the diagnosis?*
- What adjustments have you made either before, or since your diagnosis, if any?
 - *What adjustments have you made in the things that you do in day to day life?*
 - *Have there been practical adjustments that you have made?*
 - *Have you noticed a change in your way of thinking, or how you approach things?*
 - *What adjustments have others noticed in you, if any?*
 - *What changes have you made to the roles that you take on?*
 - *How did you know that you were adjusting (or had adjusted) to living with cancer? What did you notice?*
 - *How would you know that you are adjusting?*
 - *Do you experience frustration? What is this frustration aimed at? How do you cope with it?*
 - *Upon reflection, are there any aspects of the adjustment process that particularly stand out for you?*
- How did you realise the adjustments you needed to make?
 - *How did you cope with making these adjustments?*
 - *What did you do to aid the adjustment process, if anything at all?*
 - *What support did you receive to help you adjust to cancer? How did this help? If not, in what ways did it not help?*
- Have you noticed any changes in your relationships?
 - *Has your family played a role in your adjustment, if so could you explain?*
 - *Has your relationship to yourself changed in any way, if so could you explain?*
 - *What was the reactions of other people? How have you dealt with these?*

- *Have you noticed any changes in people's expectations of you or your adjustment to head and neck cancer?*
- *Is there anything that anyone has said or done that has been particularly helpful or unhelpful?*
- Do you feel there has been a difference in adjusting to the visible and not visible aspects of your head and neck cancer?
 - *What has been involved in adjusting to visible aspects?*
 - *What has been involved in adjusting to the invisible/functional aspects?*
 - *What has been different about them?*
- What have been some of the challenges in making adjustments?
 - *How did you try to cope with these challenges? Did this work?*
 - *Are there aspects that you feel you haven't adjusted to? What would need to happen?*
- Is there anything else that we have not mentioned that seems important to discuss?

General prompts:

- *Please tell me some more about that*
- *Please tell me what you're thinking about that question*
- *Can you give me an example if possible?*
- *What did you do/think when....happened?*

Third Interview Schedule

- What does the term 'adjustment' mean to you?
 - *When you hear the term 'adjustment', what comes to mind?*
 - *What changes have you noticed in yourself, if any?*
- When you first noticed something was wrong, how did you react?
 - *Were you expecting a cancer diagnosis?*
 - *How did you manage the diagnosis?*
 - *Did anything help you to start to cope with the diagnosis?*
- What adjustments have you made either before, or since your diagnosis, if any?
 - *What adjustments have you made in the things that you do in day to day life?*
 - *Have there been practical adjustments that you have made?*
 - *Have you noticed a change in your way of thinking, or how you approach things?*
 - *What adjustments have others noticed in you, if any?*
 - *What changes have you made to the roles that you take on?*
 - *How did you know that you were adjusting (or had adjusted) to living with cancer? What did you notice?*
 - *How would you know that you are adjusting?*
 - *Do you experience frustration? What is this frustration aimed at? How do you cope with it?*
- Was there a moment that you decided that you needed to make some adjustments or changes?
 - *Was there an event that triggered you realising that things needed to change?*

- *What changed after that?*
- *How/where did you find the strength to make these adjustments?*
- *How did you cope with making these adjustments?*
- *What did you do to aid the adjustment process, if anything at all?*
- *What support did you receive to help you adjust to cancer? How did this help? If not, in what ways did it not help?*
- Do you feel that there was a difference in how you initially coped with the diagnosis and treatment to how you coped during recovery?
 - *What was different about how you coped or adjusted initially and later?*
- Have you noticed any changes in your relationships?
 - *Has your family played a role in your adjustment, if so could you explain?*
 - *Has your relationship to yourself changed in any way, if so could you explain?*
 - i. *In what way?*
 - ii. *Was this helpful? In what way?*
 - iii. *What do you do/think now that you didn't before?*
 - *What was the reactions of other people? How have you dealt with these?*
 - *Have you noticed any changes in people's expectations of you or your adjustment to head and neck cancer?*
 - *Is there anything that anyone has said or done that has been particularly helpful or unhelpful?*
- Some people have said that 'acceptance' has helped them to adjust to their experiences, do you feel this has been the case for you?
 - *What aspects of your experiences have you used acceptance for?*
 - *How/where did you find the strength or motivation to accept your experiences?*
 - *What did you have to do to accept it?*
 - *Did you notice a change in your emotions and thoughts when you came to acceptance?*
 - *What did the acceptance do to your feelings towards yourself?*
 - *What do you do/think now that you didn't before?*
- Do you feel there has been a difference in adjusting to the visible and not visible aspects of your head and neck cancer?
 - *What has been involved in adjusting to visible aspects?*
 - *What has been involved in adjusting to the invisible/functional aspects?*
 - *What has been different about them?*
- What have been some of the challenges in making adjustments?
 - *How did you try to cope with these challenges? Did this work?*
 - *Are there aspects that you feel you haven't adjusted to? What would need to happen?*
- Is there anything else that we have not mentioned that seems important to discuss?

General prompts:

- *Please tell me some more about that*
- *Please tell me what you're thinking about that question*
- *Can you give me an example if possible?*
- *What did you do/think when....happened?*

Fourth Interview Schedule

- Describe/talk through the model
 - *Discuss each theme – what are your thoughts about this?*
 - *Does it make sense to have... [seeking validation of the connections I have made in the theory]*
 - *What do you think of the idea of 'modifying your relationship to the changes cancer brings'?*
 - *Does this fit with your experiences?*
 - *Is there anything that does not fit with you?*
 - *Is there anything that feels is missing from the model or that you would change?*
- What adjustments have you made either before, or since your diagnosis, if any?
 - *What adjustments have you made in the things that you do in day to day life?*
 - *Have you noticed a change in your way of thinking, or how you approach things?*
 - *How did you know that you were adjusting (or had adjusted) to living with cancer? What did you notice?*
- Are there particular emotions that you have to try to manage? How do you cope with these?
 - *Some people have tried practical strategies, or sought support from friends/family*
 - *What do you get from talking to other people?*
- Some people have spoken about a specific moment about making a choice that things needed to change, and some have spoken about a gradual change – does either of these fit with you?
 - *Was there an event that triggered you realising that things needed to change?*
 - *What changed after that?*
 - *What did you do to aid the adjustment process, if anything at all?*
 - *What support did you receive to help you adjust to cancer? How did this help? If not, in what ways did it not help?*
- Some people have said that 'acceptance' has helped them to adjust to their experiences, do you feel this has been the case for you?
 - *Do you see acceptance feeling in to these other things? (developing own understanding, making changes etc)*
 - *Is there anything that you have done to help you to reach acceptance?*
 - *How/where did you find the strength or motivation to accept your experiences?*
 - *What did you have to do to accept it?*
 - *Did you notice a change in your emotions and thoughts when you came to acceptance?*
 - *What did the acceptance do to your feelings towards yourself?*
 - *What do you do/think now that you didn't before?*

- Some people have spoken about trying to regain a sense of normality by re-finding what their purpose and values are – is that something that resonates with you?
 - *Are there things that you have done to regain some normality?*
- What have been some of the challenges in making adjustments?
 - *How did you try to cope with these challenges? Did this work?*
 - *Are there aspects that you feel you haven't adjusted to? What would need to happen?*
- Is there anything else that we have not mentioned that seems important to discuss?

General prompts:

- *Please tell me some more about that*
- *Please tell me what you're thinking about that question*
- *Can you give me an example if possible?*
- *What did you do/think when....happened?*

Appendix 12: Demographics Information Form



Demographics Information Form

(Final version 1.1: 06.07.2017)

Title of Study: How do patients adjust psychologically to the experience of head and neck cancer?

IRAS Project ID: 216710

Name of Researcher: Louise Calver

Participant ID:

Age: Gender:

Ethnicity:

Is this your first experience of cancer?

Location of head and neck cancer:

.....

Date of diagnosis:

Treatment type (if applicable):

Treatment completion date (if applicable):

Have you received any psychological support in relation to your head and neck cancer? If so, please briefly describe this:

.....

.....

.....

Do you have cancer in any other sites other than head or neck?

.....

.....

Marital status:

Employment status:

Who do you have as support?

.....
.....

Do you have any mental health problems?

.....
.....

*Do you have a history of any mental health problems before your head and
neck cancer diagnosis? Please specify:*

.....
.....

Appendix 13: Transcript Example with Open and Focused Codes

Transcript 4.

Excerpt 1

P: But I'm not the same person I was before I had cancer.

I: OK. So maybe your definition of normal is a little bit different now?

P: It's, yes, I'm not sure whether normal's the right word, it's just who I am now, compared to who I would have been, had I not had cancer, I suppose.

I: OK. So are you saying that the adjustment is the living with the person you are now?

P: Yes.

I: And maybe making some changes that you wouldn't have had to make before the cancer?

P: Yes, or just accepting that there are certain things in my life now that will always be there, you know. If I look at my wrist it looks, my wrist and my arm are a patchwork quilt, you know. Just, you know, every morning I shower, I've got a great scar here where the feeding tube runs in, you see it every day. You know, I've got this usual goaty beard because I did Movember a while ago, but I can't grow a full beard because this side of my face has got no hair on it because of the radiotherapy. So that's as wide as I can get a beard to go, otherwise, it looks really stupid, other than just this stupid little thing. Just things that, I suppose, you've met me for the first time, you possibly, I don't know, don't look at me and go, oh there's a guy who had cancer. You just see a bloke in a suit, you know, just a bloke. So in that way I'm quite fortunate and, you know, I've got no massively outward signs, you know, I've got a scar that runs from there round to there but the surgeon did such a good job that it looks like a crease in my neck.

I: Yes, it's incredibly neat.

P: Yes. So, you know, it's, there are things that I adjust to that people don't see, if you know what I mean?

I: Yes.

P: You just have to get used to it and deal with it.

Open Coding

Normal again
Not the same as before

Normal vs who I am now

Accepting reminders of
cancer

Adjustment is accepting
differences

Scar and beard are reminders
of cancer

Cancer isn't noticeable

Fortunate – no obvious
outward signs of cancer

Adjusting to unseen things

Get used to and deal with
effects

Focused Coding

Living with the new me

Redefining normal

Accept the presence of it – it
is what it is

Accepted the scars

Scar as a reminder

Dealing with reminders

Absence of visible
difference – blessing and a
curse

Absence of visible
difference – blessing and a
curse

Unseen aspects most
difficult to adjust to

I: Yes. So that was going to be one of my questions actually, do you feel that there's sort of a difference between adjusting to visible and non-visible aspects?

P: I would think so and possibly, for the good and for the bad. So if I had, if I'd got a physical thing that was obviously, you know, like I say, if, on holiday I'm covered in scars and bits and, you know, went on holiday this summer with some friends and their kids. And, you know, the parents having to explain to the kids why (Lawrence) got scars here and has got, you know, what they were all about, sort of thing. But, you know, you have a conversation with somebody and cancer comes up, oh you couldn't tell, as opposed to, I suppose, having a great big scar you can see, it's more visible. Whether it's a good thing or a bad thing I don't know because I only know what I live with.

I: Yes. So how about your adjusting to the things that you can't see? Because that sounds like it's, that's most, there's some things that you see but that's sort of because you see yourself undressed and you have that reminder. But adjusting actually to some of those functional differences?

P: You just have to get on with life, you know. I never, it was daft, the whole thing, I never used to go to bed and have a glass of water. Now I wake up in the morning and my mouth is so dry and, occasionally, I wake up in the middle of the night, not so much now but certainly, earlier, and it would be like, literally, couldn't talk because, you know. So glass of water and you're fine. There's certain practical things you just have to adjust to, which again, I suppose, yes, a large proportion of the population may go to bed with a glass of water anyway and to them it's not, that's quite normal.

I: Yes, but for you it was an adjustment?

P: Yes.

I: OK.

P: And sometimes it's still a reminder. Go to bed, oh I've forgot, I haven't brought a glass of water with me, I have to go back downstairs, get a glass of water. Why are you doing that? Because you've had cancer. Everything, not everything comes back to that, that's not fair, there are a lot of little things that remind you all the time. On holiday last week with some friends, and I don't know whether you were watching, was it Chanel 4 or something, they had a Stand Up for Cancer Gogglebox thing that was on.

I: I saw it advertised.

Good and bad aspects of visible/invisible effects

Visible changes need explaining

Unsure if no visible signs is better or worse

Adjusting – just get on with life

Practical changes and adjustment – but small

Changes are a reminder of cancer

Lots of little reminders of cancer

Absence of visible difference – blessing and a curse

Explaining to others

Carrying on

Practical changes

Adjustments incorporated into daily life

Developing a new routine

Dealing with reminders

P: Yes. Well I tend to avoid those sorts of things. And these friends wanted to watch it and they had it on and, you know, so that's a constant reminder. And then whether it was just bad luck, but they then had little clips, a young child who had cancer and died, and this woman who had got kids had cancer and died. And, obviously, they're trying to invoke, you know, pluck people's heartstrings to donate and stuff. And I find that sort of stuff, and I know it's got to be done, it just winds me up. You know, without saying out loud, which I don't know if that's good or bad or not, it was like, you know, not everybody with cancer dies.

Excerpt 2

P: Yes. So, you know, things like that, always making sure I've got water on my desk at work because your mouth gets dry, then talking becomes more difficult. You know, you sort of, your tongue feels like it's swelling up, sort of thing. Things like that, you know, just, not massive adjustments, but just things that you have to do.

I: Yes. So you said that before, you started to see (psychologist), you were feeling just really angry and frustrated?

P: Short tempered, I found I was very short tempered and quick to feel angry. Not portraying it but, you know, the kids would do something and I would get angry with myself because I knew I was getting angry with them, more than what they were doing required, if you know what I mean. I shouldn't have been feeling the way I was feeling and that was my frustration, just because my patience had gone because I was constantly frustrated with myself.

I: OK. So actually, that frustration with yourself made it really difficult to deal with anything else?

P: Yes. The way (psychologist) described it to me, which, again, helped me to understand it a bit, was imagine you've got a bell jar and it's full of all these things that you're dealing with, and it gets very full to the top and then somebody puts something in extra, however small it is, there's no more room. So you've got to learn to let something out of the bottom, otherwise, you can't put anything else in the top. That my head, as small as it is, just can't deal with it.

I: Yes. There's just no room, you can't make room?

Avoid TV cancer campaigns
Reminder of cancer
TV and public perception of cancer

TV portrayal of cancer
winds me up

Remind – not everyone with cancer dies

Ensuring availability of water

Making small, practical adjustments – just have to

Noticed getting angry with children – needed to change

Sought therapy because of short temper

Short-tempered due to frustration at self

Psychologist helped

Understanding stress and learning to manage it

Understanding you can't deal with everything

Avoid difficult situations

Dealing with reminders

Consider mortality

Adjust everything – affected life
Practical strategies

Noticing changes in emotions

Understanding reasons for emotions

Dealing with frustration

Understand reasons for emotions

Validating emotional experience

P: No, and that made sense. As I say, some of it was just a case of, I think some, in my case with (psychologist) anyway, some of the, I said this to her politely, the same goes I was with you, you're not part of my life, I may never see you again. So if I tell you something here, you're not going to sit at the, you know, at the Christmas dinner table and something comes up and you go, oh I remember (Lawrence) said something, look at me, is that, I can be completely open and relaxed knowing that, whether you form an opinion about me or not, actually, it doesn't make a great deal of difference to my life because you're not part of my life, in the nicest possible way.

I: Yes, because it's not going to come back on you, yes.

P: Whereas, if I, this is irrelevant, but let's say I admitted to my wife that if somebody says the word, blue, it makes me upset because it makes me think of cancer, just as a practical. And then we're sat at the dinner table and somebody goes, oh blue, blue, blue, blue. She's going to look at me like, oh how is he? So, but I could say that to you here because it wouldn't make any difference. And then if somebody says, blue at the dinner table, it upset me, I can hide it and deal with it and not have anybody else worrying about me.

I: Yes, OK.

P: If that makes sense?

I: Yes. So it's almost, in a way, what information you share with who?

P: Yes. It's good to have somebody who is outside of your normal life to admit your fears, etc., to.

I: OK. So maybe to actually have that outlet, where you can let them out somehow?

P: Yes.

I: But, so that it's not going to continue to impact on your life because

P: Yes, and you don't want, you don't want loved ones worrying about you. You put on, certainly, I do this, as much of a brave face as you can because you know very well, the people who care about you are going to be worried sick anyway. They're not going to want to show it to you because they want to be supportive, and you're then sort of putting all of your concerns and worries onto them, you're making their life more difficult. And they haven't got cancer, you've got it. They're part of it because they're in your life and they love you, but you don't want to make their life any more difficult than you already

Don't want family to remain sensitive to struggles	Choose who to share things with
Not sharing everything with family Sharing feelings with someone not part of his life	Talking openly to accept and process it
Talking to someone not involved – more open and relaxed	
Don't want family to remain sensitive to struggles Let feelings out but not worry family – can hide it Not sharing everything with family Sharing feelings with someone not part of his life	Choosing who to share things with Not talking to avoid others' reactions
Admit fears to someone outside of normal life	Choosing who to share things with Talking to accept and process it
You don't want loved ones worrying about you Put a brave face on – people are already worried Make life easy as possible for others - don't put on them	Choose who to share things with Not talking to avoid burdening others
Others hide their worries to be supportive	

have because you've already thrown a hand grenade into their world and gone, hello, guess what, boom. You've now got to deal with this, it's not, you haven't got this problem, I have, but you've now got to deal with it with me. And you want to try and make it, well I want to try and make it as easy as possible for the people around me. So I don't want them, I don't want to put onto them anymore than I need to.

Excerpt 3

- I: So you said the sort of sitting in the car and screaming, was one way of dealing with that, did you have any other ways of dealing with that?
- P: No, other than, you know, life's not fair, accept the fact that life's not fair because however many people complain about the fact that life isn't fair, it isn't. And there are an awful lot of people in a lot worse situations than me. I've got a lovely family, I've got a decent job, OK, so I've had cancer, at that point I had cancer. You know, there's people get blown up, people who've never had, you know, haven't made half the life I've had, you know, die as children. There's so many people who are so much worse off than me, that you can't wallow in that much self-pity. You're allowed a little bit but, you know, I'm not the world's worst person, you know, the worst off person.
- I: So maybe it's a bit about allowing yourself to have that feeling because it's a valid feeling of, it's not fair?
- P: Yes.
- I: But then also, sort of picking yourself back up and be like, but
- P: Yes counterbalancing it, yes. But even facing my surgery, there would have been an awful lot of people in the world who would say, I'll swap places with you, I'll swap places with you tomorrow, you know. I've got no arms, no legs, you know, whatever these people, there are people who would have swapped places with me the day of my surgery, when I might not have woken up off that table, guaranteed, because I'm not in the worst place. There are people who are worse off than me.
- I: OK. So maybe it's sort of thinking about that sometimes as well?
- P: Yes.

Others are also dealing with your cancer

Don't want to put on family more than already have

Worry about impact on others

Accept that life's not fair

Allow some self-pity

Finding the positives

Others are worse off – positive thinking

Accept the presence of it - it is what it is

Validate emotional experience but don't wallow

Focus on what I do have

Others are worse off

Counterbalancing positive and negative emotions

Others are worse off

Putting things into perspective

Others are worse off

Excerpt 4

I: So is there anything that you did to start to try and cope with the diagnosis?

P: I, what worked for me, from almost, well as far as I can remember anyway, from finding out what was going on, from when I sort of felt like I can remember, you know, I got back to normal, for want of a better word, was taking it either day by day, half day by half day, even down to hour by hour, just, you know, OK, I'll get through to lunchtime. I've made lunchtime, right, OK, I'll get through to 3 O'clock or I'll just get, if I get through to bedtime, that's another day done. And just narrowing my, narrowing my vision down to as close, you know, as close as I needed to, just to, because thinking about it all is very difficult sometimes. So it's just like, right, well what have I got to do to get through today? I've got to get up, I've got to do this, this and this. And if I do all that, I'll go to bed, I've done a day. That's another day I've ticked off, that's another day closer to when it's all over.

I: OK.

P: So that's what I did.

I: Yes. So was there anything that changed to make it whether you were doing hour by hour or day by day?

P: I suppose just, how it's just, much stuff you've got to get it done and how well you felt like you were coping with things.

I: OK. So it just varied on how you were feeling that day?

P: Mostly, it was just get to the end of the day, for me, you know. When I was on radiotherapy, yes, OK, so get up, everybody goes to work, I was getting picked up probably around about 11 ish for my radiotherapy. Make sure you're ready for 11

Back to normal – split day into sections
Cope day by day until it's over
Narrow down vision to get through

Difficult to think about it all
Narrow down vision to cope
Set small goals of getting through
Break the day down into tasks

Breakdown of sections depend on coping and tasks

Aim to get through the day
Breakdown tasks to get through the day

Tackle one things at a time

Focus on the present and immediate future

Retain as much normality as possible

Setting small goals
Tackle on thing at a time

Excerpt 5

I: Yes. So it sounds like, actually maybe setting some of your own little goals and working towards them

P: Helps.

I: Yes, OK. So is that still a process that's going on now for you or?

P: I don't think so. Like I say, I'm officially cured, which just now means I live with the after effects. I try not to worry about it. I've done the whole, what caused it? One of the biggest frustrations for me is what caused it. So if I'd smoked forty a day and drunk a bottle of whiskey, I could stop smoking, stop drinking and reduce the risk of it happening again. I didn't do any of that. So I don't know what it was that triggered it. It could be nothing at all. It could be, I don't know, it could be blue smarties, you know. So I don't, one of the things that took me a while to accept or adjust or forget, for want of a better word I suppose, was accepting the fact that I don't know what caused it. So I don't know if I'm doing something now, which could be opening it up again to it coming back. And that was very scary to start with. Like I say, you know, does diet coke, is diet coke causing the cancer, is it, it could be anything. Because, you know, we're individual and what reacts to you might not react to me. So that, that took a while to deal with. That was quite early on though and that was just something you just have to, look, accept you don't know, the doctors don't know, nobody knows. So again, you're banging your head against a brick wall to try and get, if you're going to get frustrated by this, because you don't know.

I: So was there anything that was helpful for you to begin to start accepting that you just don't know? Because it sounds like maybe you had a bit of a word with yourself every now and then?

P: Yes, it's just, you know, if I was getting to the point where I felt frustrated or, for me, the time that you can never lie to yourself is last thing at night when you're going to bed. Everybody's asleep, you're lying there in bed, and there's just you and your head. There's nobody to talk to particularly, you know, my wife's asleep or what have you, and if you can't sleep, that's the time that things rattle around in your head and, you know, the demons or whatever you want to call them, say, oh have you thought about this? You know, and you find yourself lying there thinking about stuff and, you know, getting a bit clammy, you know, whether that's a mild panic attack or not, I don't know. But, you know, for god's sake, you can't do anything, you know, what's the best you can hope for in this scenario? You're going to lie there and go, oh it's that that's caused it. Well that's not going to happen, you know, people who are a damn site cleverer than you don't know. So what is going to happen if you keep thinking about this? You're going to just get really tired and grumpy and frustrated, try and think about something else, because you can't, it's not solvable.

Cured – living with after effects
No longer setting goals to cope
Doesn't engage in risk factors
Biggest frustration if what caused it
Try not to worry

Can't reduce risk of recurrence
Accept unknown cause
Could be doing something to make it come back

Early on - recurrence fears
Learn t accept recurrence fears
Frustration

Can't lie to yourself at night

Night time is hard – think and panic

Annoyed with self for worrying – can't do anything

Self-coaching – talk to self

Think about something else –it's not solvable

Adjustment is ongoing

Questioning where it came from

Dealing with frustration

Accepting the unknown

Accept what you can't change

Self-coaching

Practical thinking

Accepting the unknown

I: Yes.			
P: You know, I can't strike a match in a jelly. There's just some things you can't do.	"There's just some things you can't do"	Accept what can't be changed	
I: Yes, OK.			
P: So I can't solve this problem because nobody knows.	Problem is unsolvable		
I: Yes.			
P: So try and, as best you can, to not think about it because it will just send you mad.	Try not to think about it – don't go mad	Don't overthink or guess	
I: Yes. So maybe, as you said, just having that reminder to yourself that you don't know and you can't know. So driving yourself crazy about it is not going to achieve anything.			
P: No. What's, you know, worrying about it isn't going to change it. So what's the point? You know, you can't stop yourself worrying all the time but sometimes you just have to say to yourself, hang on a minute, take a deep breath, you know, breathe in, breathe out, breathe in, breathe out, relax, calm down and let's move on, because you can't change it.	Accept and move on – can't change it Worrying won't change it Can't always stop worries Coach self to breathe and move on	Accept what can't be changed Self-coaching Don't overthink or guess	
I: Yes. So maybe sort of coaching yourself through it a little bit?			
P: Yes.			
I: So we've spoken about some of the practical adjustments and the maybe, coaching yourself through some difficult things. Have you noticed a change in the way that you think or the way that you approach things?			
P: I certainly, so life wise, I moved job, went for my job interview and said to my interviewees or interviewer, not sure which way round it is, if you offer me the job that's great but I want to let you know, I take my son to school every morning, he doesn't get to school until, the earliest I can drop him off is ten to nine, I work in Chesterfield, I won't get to work until half past nine. So if you offer me this job, understand that those are the terms and conditions I accepted the job. And I try, I do occasionally find myself having to have a word with myself, I try not to do long hours anymore. I try to leave work at a reasonable time, you know. Before I was ill, I had a lot people saying, you know, life's short, you know, and all that sort of stuff, but it is and it's quite fragile. And so I try to do things with that in mind a bit more, I suppose, than I did. You know, you say it, everybody says it, some people more successful than others, but, you know, until such time as you have, you know, faced your own mortality properly, you know, I was forty when I was diagnosed, that's young.	Moved job Try not to work long hours now Life is short - live with this in mind Bear in mind life is fragile Faced own mortality	Change in approach and thinking Change in outlook	

I: It is, yes.			
P: To actually go, I could be dead in three months. I mean, as I said to you before, the lymph nodes, when they took them out, so I'd had no, so I'd seen my dentist in the May or June, because I met her the other day in town on a night out, and she was drunk and crying and apologising that she didn't see anything. I was like, there's nothing there, it's not your fault, there's nothing there to see. So this ulcer came up roughly in the July, I had the surgery about the back end of September, I think it was, you know, pretty quick, from nothing to physical manifestation to surgery. It had already spread into my lymph nodes but hadn't gone into the membrane to then, obviously, spread around my body.	Consider mortality – could be dead in 3 months		
I: OK.	There was nothing to notice for diagnosis All really quick but didn't spread around body From nothing to surgery – very quick	Speed of changes	
P: But you think about it, to my brain, and again, I'm not, I'm not asking about this, but to my mind you go, well if in that short space of time it went from there to there, you're quite lucky that, you know, another week, another two weeks, another month, you might not be here. Because, obviously, it's an aggressive little sucker that was, that you'd got, you know, that took adjusting to.	Lucky that it was noticed – could have spread quickly Adjust to idea of how aggressive cancer was Might not be here if wasn't found quickly	Consider mortality Putting things into perspective Feeling lucky and unlucky	
I: Yes.			
P: You know, just accepting that. But that's why I say, I'm unlucky that I got it but I'm also quite lucky because of where it was and how quickly I was seen and dealt with and, you know, it hadn't spread, that's lucky.	Accepting how aggressive cancer was Unlucky that had cancer vs lucky it was noticed and not spread	Accepting – it is what it is Feeling lucky and unlucky	
Excerpt 6			
I: So what made you realise that actually, you really do need to do something?			
P: So saying to the kids, for example, pick that up off the floor you've just dropped, walk out the room, come back and it still being there and flipping my lid. And then looking at (son) looking at me like, wow, hang on, that's, it's a sweet wrapper on the floor, what the hell have I just, wow. And then walking upstairs and just sort of going, that's not right, that is not, you don't want your son looking at you with that, Jesus, that's a bit heavy dad. It's a sweet wrapper, you know. You said pick it up, I'll pick it up, OK, I didn't do it immediately but wow, hang on. And that was the point, OK, this is not you, this is not how you dealt with things before, something is not right here. You are not, and I don't want to be, that's not how I want to live the rest of my life. I do not want to be short tempered like	Notice need for help due to flipping at small things Thinking how I responded was not right Don't want son to look at me like that Realising dealing with things differently – something is not right Don't want to be short-tempered for rest of life	Turning point Noticing changes in emotions Make a change or be unhappy Deciding what you want for yourself	

that for the rest of my life. I want to be me, the old me, or as much as the old me I can get to, hence, the whole thing I was talking about, understanding, actually, what I wanted to do I couldn't get to. And then accepting, actually, no, this is the new you and, for want of a better word, open the valve at the bottom of that jar and let an awful lot of rubbish out, closing it again, there's still a lot in there, there's still stuff that bubbles to the surface. Almost on a daily basis something will happen or, you know, something can happen.

I: Yes.

P: But generally, been a lot happier with the way I generally deal with things.

I: Yes. So how did you sort of open that valve and let all of that stuff out?

P: I don't really know. Talking to (psychologist) was an almost, I don't know whether just saying these things out loud and just getting them off your chest, whether it's just hearing me say them and your brain actually listening, going, OK, well you're talking rubbish now, aren't you? You know very well you can't ever be the person that hasn't got cancer because you have had it, you prat. You know, and just, I don't know whether it's just realisation or what. You know, I remember, I said to her, you know, thanks for helping out. She went, I haven't really done a lot, you've managed this yourself. I don't know whether it was literally, just facing it and just acknowledging, actually, this isn't right, talking to somebody about it and then that just made me realise what was going on. The honest answer is, I don't know.

I: OK. So maybe it was a bit of, we're not sure how that realisation came across but sort of, almost that arrival of that realisation was, potentially, even if we don't really know how it happened?

P: Yes. As I say, to me, it was the accepting that I'm on a different road, is the only way I can describe it, you know, I'm just on a different road now.

I: Yes. And that was through talking?

P: Yes, just talking, yes. I'll always be (Lawrence) that had cancer, they'll always be things that bug me, you know, and they'll always be reminders on a daily basis, but most of the time I just deal with it. Just go, that's life, that's me now, you know. You can't change it, so get on with it. There's no point in trying to change things that you can't change

Want to be the old me Understanding what is achievable Wanting old me but accepting new me Accepting new me – letting stresses out Still lots of stress – daily things to deal with	Accepting back to normal isn't possible Accept what can't be changed Understand reasons for emotions
Happier with how dealing with things now	Change strategies for dealing with emotions
Saying things out loud is helpful – get them off chest Listening to self out loud – realised can't be same as before Talking about it – facing it and realising what is going on	Talking to process and accept it Validate emotional experience Understand reasons for emotions Accept what can't be changed
Accepting the different road	Accepting back to normal isn't possible
There will always be reminders of cancer That's me now Can't change it so just get on with it Don't try to change things you can't	Accept what can't be changed

Appendix 14: Descriptive Themes

Descriptive themes for Batch 1

Reminder of Aims:

To develop an understanding of how patients adjust psychologically to head and neck cancer.

Themes Batch 1 (Walter, Bruce & Eve)

Nature of adjustment

- Adjustment starts before diagnosis
- Adjustment is ongoing
- Adjustment is uncertain and fluctuating – unknown tunnel with an unknown end

Defining adjustment

- Coming to terms – understanding and accepting what will happen
- Learning to cope daily
- Carrying on
- Getting back to normal
- Understanding how things have changed
- Not everything is about cancer

Initial reaction to diagnosis

- Shock
- Expected

Talking vs not talking

- Managing others' expectations
- Managing others' reactions
- Talking to help process it
- Not making others feel awkward
- Don't want to deal with it

Making a choice

- To change or be unhappy
- Deciding what you want for yourself
- To fight or to accept

Balancing act

- Thinking positively vs feeling sad
- Accepting vs fighting (functional changes)
- Preparing for the future vs not overthinking
- Carrying on vs taking a break/making changes

Avoid difficult situations

- Eating out
- Socialising (initially)

These seem to
Overlap somewhat

Positive thinking

- Maintaining hope for the future
- I'm ok today
- Focusing on retained abilities
- Focusing on achievable activities

Thinking and planning

- Compartmentalise challenges
- Tackle one thing at a time
- Dealing with things immediately
- Focus on the present or immediate future
- Don't overthink or guess
- Practical strategies – approaching things differently

Asking for support

- Learning to ask for and accept help
- Change in roles
- Therapy

Getting family and friends on board

- Explain so family understand
- Dealing with others' lack of understanding
- Not shutting them out
- Getting through it together
- Change in relationships

Information gathering

- Asking experts
- Asking those who have been through it
- Knowing what to expect
- Knowing what is normal experience
- Develop own understanding

Attending peer groups

- Learning to express feelings
- Advice on management strategies
- First step in socialising
- Sharing experiences

Fighting the fatigue

- Managing time differently
- Practical tactics
- Just carry on
- Expect to expend more effort and energy
- Explaining fatigue to others

Dealing with distressing emotions

- Normalise experience of negative emotions

Re-categorise as:
Remaining in
the present?

Overlap?

- Expect to feel low, frustrated angry
- Give yourself permission to feel negative emotions
- Frustration

Dealing with loss

- Loss of planned future
- Loss of physical abilities
- Loss of anatomy
- Loss of role and aspects of self

Dealing with recurrence fears

- Positive self-talk
- Mindfulness/focus on the present
- Put it to the back of mind
- Learning that not everything is a sign of cancer

Unhelpful aspects

- Playing the ‘what if’ game
- Questioning where it came from
- Ignoring it

Taking time

- Acknowledge the time it takes to improve
- Give yourself more time to complete tasks
- Taking ‘time out’

Barriers to adjusting

- Cancer is unseen vs seen (different barriers)
- Ongoing cancer effects are not understood
- Effects of cancer are constant (dry mouth/eating)
- Others’ expectations to be ‘alright’
- Daily fluctuations
- Finding motivation (keep trying, carrying on)
- Guilt
- Shock

Effects of adjustment

- New person – change in confidence
- Changed family relationships
- Pride at coping
- Change in thinking – can’t help others before help self

Noticing successful adjustment

- Enjoyment returns
- Socialising more
- Don’t dip as far

Recognising impact and magnitude

Realistic and accurate expectations of ability

Regaining/retaining normality/routine

Noticeable differences

Functional differences

Learning to live with the new me

- A new way of life

Reconnecting

- Enjoying previous hobbies
- Socialising with previous people

Descriptive themes for Batch 1 & 2

Reminder of Aims:

To develop an understanding of how patients adjust psychologically to head and neck cancer.

Themes Batch 1 & 2 (Lawrence, Sebastian, Raymond)

Nature of adjustment

- Adjustment starts before diagnosis
- Adjustment is ongoing
- Adjustment is uncertain and fluctuating
- Adjustment during recovery; return to normality
- Adjustment goal
- Adjustments need to be incorporated into daily life

Defining adjustment

- Coming to terms
- Learning to cope daily
- Carrying on
- Getting back to normal
- Not everything is about cancer
- Adjust life, not just cancer

Noticeable differences

- Scars are unpleasant initially
- Need explaining; people look
- Better than predicted
- A reminder of cancer
- Unimportant because I am alive
- Absence of visible differences – a blessing and a curse

Internal/mental adjustments

Recognising the impact and magnitude

- Recognising the magnitude of the cancer and treatment
- Time period to recover
- Recognise normality of struggling
- Understanding the psychological effects
- Developing realistic expectations

Acceptance

- 'back to normal' isn't possible
- Choose your battles
- Need to slow down/take time
- Living with recurrence fears
- Can't stop worries and emotions

Acknowledge the negatives

- Emotions
- Possibility of death
- Physical limitations

Change relationship with self

- Recognise and praise achievements
- Self-talk/coaching
- Be kind to yourself
- Understand and listen to body

Making a choice

- To change or be unhappy
- Deciding what you want for yourself

Balancing act

- Thinking positively vs feeling sad
- Accepting vs fighting (functional changes)
- Preparing for the future vs not overthinking
- Carrying on vs taking a break/making changes

Positive thinking

- Maintaining hope for the future
- I'm ok today
- Focusing on retained abilities
- Focusing on achievable activities
- Consider the alternative (death)

Thinking and planning

- Compartmentalise challenges
- Tackle one thing at a time
- Narrow down vision
- Dealing with things immediately
- Focus on the present or immediate future
- Don't overthink or guess
- Practical strategies – approaching things differently

Observable changes/adjustments**Asking for support**

- Learning to ask for and accept help
- Changes in roles

- Therapy

Taking time

- Acknowledge the time it takes to improve
- Give yourself more time to complete tasks
- Taking 'time out'

Attending peer groups

- Learning to express feelings
- Advice on management strategies
- First step in socialising
- Sharing experiences

Talking vs not talking

- Managing others' expectations
- Managing others' reactions
- Talking to help process it
- Not making others feel awkward
- Don't want to deal with it
- Not worrying others

Fighting the fatigue

- Managing time differently
- Practical tactics
- Just carry on
- Noticing and stopping
- Expect to expend more effort and energy
- Explaining fatigue to others

Understanding and Explaining

Getting family and friends on board

- Explain so family understand
- Dealing with others' lack of understanding
- Not shutting them out/getting through it together
- Change in relationships
- Family are a passive comfort

Information gathering

- Asking experts
- Asking those who have been through it
- Knowing what to expect
- Knowing what is normal experience
- Develop own understanding

Dealing with experiences

Dealing with emotions

- Normalise emotional experience
- Give yourself permission to feel rubbish

- Don't wallow
- Let emotions out/share emotions
- Hide some emotions
- Understand reason for emotions
- Frustration

Dealing with loss

- Loss of planned future
- Loss of physical abilities
- Loss of anatomy
- Loss of role and aspects of self

Dealing with recurrence fears

- Positive self-talk
- Mindfulness/focus on the present
- Put it to the back of mind
- Learning that not everything is a sign of cancer
- Learning what is normal
- Seeking medical advice/explanation

Dealing with reminders

- Scars
- TV campaigns
- Physical limitations

Adjustment difficulties

Unhelpful aspects

- Playing the 'what if' game
- Questioning where it came from
- Ignoring it

Barriers to adjusting

- Cancer is unseen vs seen (different barriers)
- Ongoing cancer effects are not understood
- Effects of cancer are constant (dry mouth/eating)
- Others' expectations to be 'alright'
- Daily fluctuations
- Finding motivation (keep trying, carrying on)
- Guilt
- Shock

After adjustment

Effects of adjustment

- Changed family relationships
- Pride at coping
- Change in thinking – can't help others before help self

Noticing successful adjustment

- Enjoyment returns
- Socialising more
- Don't dip as far
- Forgetting about cancer

Avoid difficult situations

Feeling lucky and unlucky

Regaining/retaining normality/routine

Notice the need to change – turning point

Initial ideas about how adjustment may be structured:

Initial response is just to cope, adjustment comes later, potentially when some sense of normality is regained (e.g. when treatment is over, and recovery is needed, or return to work) – some of this may occur when the 'all clear' or 'remission' is given.

For some, adjustment is getting back to normal as much as possible, and for some it is aimed at enjoying life with its limitations (very close in aims, but with some subtle differences?).

Initial Coping

- Day by day
- Bottle up then deal with it
- Get by and look after others first, focus on me when time
- Withdraw
- Crying
- Planning what needs to be done
- Too ill to adjust; just survive

Turning point

- See/notice impact on children
- Return of some normality
- Advice from others

Active adjustment phase?

- Acceptance (realisation, acknowledgement)
- Making a change
 - Taking time
 - Change relationship with self
 - Change in outlook
 - Seeking help
- (bringing all compartmentalised experiences together again)

Continuing adjustment (the bits that don't stop)

- Understanding and explaining
- Maintaining changes/ongoing fight
- Dealing with emotions, reminders, and recurrence fears

Descriptive themes for Batch 1, 2 & 3

Reminder of Aims:

To develop an understanding of how patients adjust psychologically to head and neck cancer.

Themes Batch 1, 2 & 3 (Peter, Arthur, Alice)

Nature of adjustment

- Adjustment starts before diagnosis
- Adjustment is ongoing
- Adjustment is uncertain and fluctuating
- Adjustment during recovery; return to normality
- Adjustments need to be incorporated into daily life
- Gradual adjustment – cumulative effect

Defining adjustment to cancer diagnosis, treatment, and effects

- Coming to terms with life changes and limitations
- Learning to cope daily
- Carrying on with daily life
- Making practical changes
- Getting back to normal
- Not everything is about cancer
- Adjust life, not just cancer

Noticeable differences

- Scars are unpleasant initially
- Need explaining; people look
- Relief - better than predicted
- A reminder of cancer
- Unimportant because I am alive
- Absence of visible differences – a blessing and a curse

Psychological adjustments

Acceptance

- ‘back to normal’ isn’t possible
- Choose your battles
- Can’t live life the same way
- Need to slow down/take time
- Living with recurrence fears
- Can’t stop worries and emotions
- The only alternative
- Learning to accept, not question and fight

Acknowledge the negatives

- Emotions
- Possibility of death
- Physical limitations

Being self-compassionate

- Recognise and praise achievements
- Self-talk/coaching
- Be kind to yourself
- Understand and listen to body

Making a choice

- To change or be unhappy
- Deciding what you want/don't want for yourself
- **Turning point**
 - Notice the need to change
 - Admitting you're struggling emotionally
 - Getting the all clear
- **Gradual change**

Putting things into perspective

- Maintaining hope for the future
- I'm ok today
- Focusing on retained abilities
- Focusing on achievable activities
- Consider the alternative (death)
- Feeling lucky and unlucky – grateful it was found
- Others are worse off
- I'm still here
- Validate own experience BUT put into perspective
- Outlook/appreciation/life focus

Thinking and planning

- Dealing with things immediately
- Don't overthink or guess
- Practical strategies – approaching things differently

Survival mode

- Compartmentalise challenges
- Tackle one thing at a time
- Narrow down vision
- Focus on the present or immediate future

Regaining normality

- Retaining normality/routine
- Regaining/retaining valued experiences
- Still the same essence
- Changed family relationships
- Change in thinking – can't help others before help self
- Enjoyment returns
- Socialising more
- Don't dip as far
- Forgetting about cancer

- Reintroducing aspects/activities

Observable changes/adjustments

Taking time

- Acknowledge the time it takes to improve
- Give yourself more time to complete tasks
- Taking 'time out'
- Understand the prolonged recovery time
- Managing time differently

Practical strategies

- Engaging in rehabilitation
- Keep occupied
- Setting goals/targets
- Self-coaching
- Developing a new routine

Talking with others

Asking for support

- Learning to ask for and accept instrumental and emotional help
- Changes in roles
- Therapy

Attending peer groups

- Learning to express feelings
- Advice on management strategies
- First step in socialising
- Sharing experiences

Getting family and friends on board

- Explain so family understand
- Dealing with others' lack of understanding
- Not shutting them out/getting through it together
- Change in relationships
- Family are a passive comfort

Talking vs not talking

- Talking to prepare others for changes in functioning and appearance
- Talking to help process it
- Not making others feel awkward
- Don't want to deal with it
- Not worrying others/protect them
- Choosing who to share what with

Seeking knowledge

- Asking experts
- Asking those who have been through it
- Knowing what to expect

- Knowing what is normal experience

Understanding and Explaining

Develop own understanding

- Recognising the impact and magnitude of the cancer and treatment
- Time period to recover and improve
- Recognise normality of struggling with emotions and physical limitations
- Understanding the psychological effects of cancer and its treatment
- Developing realistic expectations of self and abilities
- Re-learning limits & abilities

Managing emotions and distressing thoughts

Dealing with emotions

- Normalise emotional experience/expect them
- Give yourself permission to feel rubbish
- Don't wallow
- Let emotions out/share emotions
- Hide some emotions
- Understand reason for emotions
- Drawing on previous experiences/strategies
- Avoidance

Dealing with recurrence fears

- Positive self-talk
- Mindfulness/focus on the present
- Put it to the back of mind
- Learning that not everything is a sign of cancer
- Learning what is normal
- Seeking medical advice/explanation
- Minimising risk of recurrence – improving health and lifestyle

Dealing with reminders

- Avoidance
- Distancing self

Barriers to progress

Perceived unhelpful aspects

- Playing the 'what if' game
- Questioning where it came from
- Ignoring it
- Waiting
- Aspects happening too soon (returning to work/seeing disfigurement)
- Speed of change
- Awkwardness from others
- Getting information late
- Loss of confidence

Barriers to adjusting

- Cancer is unseen vs seen (different barriers)
- Ongoing cancer effects are not understood
- Effects of cancer are constant (dry mouth/eating)
- Others' expectations to be 'alright'
- Daily fluctuations
- Finding motivation (keep trying, carrying on)
- Not allowing yourself time
- Pain/feeling unwell
- Difficult emotions
- Visibility/noticeability of cancer site

Appendix 15: Core Category Criteria

Adapted from Strauss and Corbin (1990)

Criteria	Does the core category satisfy the criteria?
Is it a central phenomenon? Can it be related to all other major categories?	Yes – it relates to all other categories.
Is it abstract and broad enough to encompass the main aspects of the theory's story?	Yes – it encompasses the overall process of the patients' psychological adjustment. It is abstract enough that patients may understand it in isolation from the remained of the theory.
Does it have explanatory power?	Yes – it underpins the process that patients engaged in as part of their adjustment process.
Does it give a logical and coherent explanation?	Yes – it helps to understand why patients may engage in the types of adjustment processes that are observed. It also helps to understand the outcomes of these processes as adjustment progresses.
Does it appear frequently in the data?	Yes – the concept was present in all interviews. Patients frequently described how their relationship with the changes resulting from cancer changed over time.
Can it account for variation and negative cases?	Yes – it is able to explain why some patients may not adjust, or why adjustment may be slowed, halted, or reversed (e.g. that their relationship the changes has remained static).

Appendix 16: Example Memos

Revising interview schedule

30.11.2017

Following the initial analysis of the second batch of interviews (participants 4-6), it appeared that “acceptance” was mentioned a lot within interviews, both with people who had received psychological support, and those who had not. When participants described their experiences with acceptance, it seemed to encompass ‘acknowledging’ the unerring presence of cancer and that its presence may not be questions, but simply has to be lived with. Acceptance was commonly described as the only option, because fighting its presence (and its effects) was futile. Upon return to the first batch of transcripts (participants 1-3), this idea of acceptance was also present, though not explicitly labelled as “acceptance”, therefore this needed to be explored further. An additional question and prompts to explore acceptance were added to the interview schedule:

- Some people have said that ‘acceptance’ has helped them to adjust to their experiences, do you feel this has been the case for you?
 - *What aspects of your experiences have you used acceptance for?*
 - *How/where did you find the strength or motivation to accept your experiences?*
 - *What did you have to do to accept it?*
 - *Did you notice a change in your emotions and thoughts when you came to acceptance?*
 - *What did the acceptance do to your feelings towards yourself?*
 - *What do you do/think now that you didn’t before?*

This question and prompts will help to consider how patients experience the process of “acceptance”, how they enacted it, and whether it is a concept that is present for all patients.

Developing categories

19.12.2017

Category: “Putting things into perspective”

Within the first three interviews, patients spoke a lot about the importance of “positive thinking” when trying to cope with, and adjust to, head and neck cancer. My development and understanding of the category was not confined to only these initial interviews; they allowed me to consider the category and to identify properties and dimensions of it before I then analysed later transcripts. “Positive thinking” and “putting things into perspective” were used synonymously within the transcripts. Across nine interviews, patients described the cognitive aspects included within “putting things into perspective”:

- Maintaining hope for the future
- I'm ok today
- Focusing on retained abilities
- Focusing on achievable activities
- Consider the alternative (death)
- Feeling lucky and unlucky – grateful it was found
- Others are worse off
- I'm still here
- Validate own experience BUT put into perspective
- Outlook/appreciation/life focus

This category is labelled as “putting things into perspective” as it appears to be a more encompassing term since it describes the process that patients engaged in, which may subsequently give rise to “positive thinking”. Discussion in further interviews suggested that “putting things into perspective” may not always result in “positive thinking” as it was felt a little unkind for thinking that “others are worse off” to be classified as “positive thinking”. Nevertheless, the act of comparing oneself with others that were worse off did have positive effects on emotions and behaviours. “Putting things into perspective” also allowed patients to consider and acknowledge some of their negative feelings, which “positive thinking” would not allow. It appeared that by allowing themselves to acknowledge that they do have negative feelings, it felt more genuine than simply denying such difficult feelings in the interest of “positive thinking”.

Following discussion with the final three patients, the category was reviewed and no new dimensions were found, therefore it was considered that this category is theoretically sufficient.

Development of the grounded theory model

19.01.2018

The model currently sets out how different categories may link together and provides a hierarchical structure that identifies the main categories. However, whilst it is helpful to start to understand the potential main players in the final theory, it does not currently exist as a grounded theory model. At present it does not have any explanatory power as it could not provide an overview of the adjustment process.

From revisiting the transcripts, there seems to be different phases of adjustment. How patients adjust psychologically seems to be potentially impacted by how they feel physically:

- When feeling physically unwell and in pain – “just coping” and “getting by” is dominant
- When feeling physical ok/having energy – patients seem to be able to ‘do more’ psychologically

The theory needs to include a temporal element to be able to capture this change in focus, and to include the ‘ongoing’ nature of the adjustment, as described by so many participants.

16.02.2018

The model seems to fit well with the participant data at present, and also makes sense to professionals working within the area, though some tweaks are required to provide a better fit. From review of the nine transcripts so far, it seems that “developing own understanding” is a more central process to adjustment than “acceptance”, therefore these need to be swapped around. This makes sense as it is “talking to others” that facilitates the development of the patients understanding (either of their emotional or physical experiences) and that this understanding then in turn facilitates “acceptance” – it is much more central.

The process of “regaining normality” also needs a little tweak, because upon revisiting my transcripts, normality is not always regained in the form that it was pre-cancer. Therefore for some participants, they have regained *a* normality, though it has been redefined, potentially as a result of some of the “making changes” that occurred in the adjustment phase previously, for example, a change in outlook on life. The category “redefining or regaining normality” provides a much better fit. It seems I have a final theory to share with my final participants...at last!

Considering the fit of a core category

16.02.2018

Initial consideration of ‘acceptance’ as the core category, however, whilst this was a central component of the adjustment process, it only links to the categories that are linked to it within the diagrammatic version of the theory. Such limitations in its links and its lack of explanatory power means that it could not be a core category.

The concept of ‘balancing act’ was quite apparent in the first sets of open coding and descriptive themes, however, on focused coding this category somewhat disappeared. This was not because it was no longer pertinent to the data, more that it seemed to span several other categories and did not appear distinct enough. For example, balancing whether to talk or not talk to others, balancing whether to accept or keep fighting physical changes/limitations, and balancing only looking to the immediate future whilst still maintaining hopes and wishes for the future. All of these examples spanned other categories, making it difficult to separate it as a distinct entity – though it could be considered a core category, because this essence of ‘balancing’ aspects of their experience and psychological effort was apparent in so much of the data. Although it applies to many categories, it is not central to all categories and as such does not have explanatory; criteria which a core category must satisfy according to Strauss and Corbin (1990).

Within all of the categories, patients appear to be acting in order to fulfil some needs that the cancer experience has interrupted. Relating this to Maslow's (1970) hierarchy of needs, it may be observed that each category may relate to the patient engaging in processes to fulfil one or more needs. For example, 'survive mode' and 'instrumental support from others' may be seen as attempting to get physiological and safety needs met. On the other end, 'developing own understanding' may be understood as patients being motivated to get their cognitive needs met. This maps on well and can be seen that towards the left side of the theory, basic and deficient needs are the largest motivators, and towards right side of the theory the growth needs are more prevalent. However, 'fulfilling needs', as related to Maslow's hierarchy, may be too broad and although all themes fit well within this theory, this is potentially due to the broad all-encompassing nature of the theory. Maslow's hierarchy would likely fit well with most data and as such is not specific enough to explain the process involved within my theory.

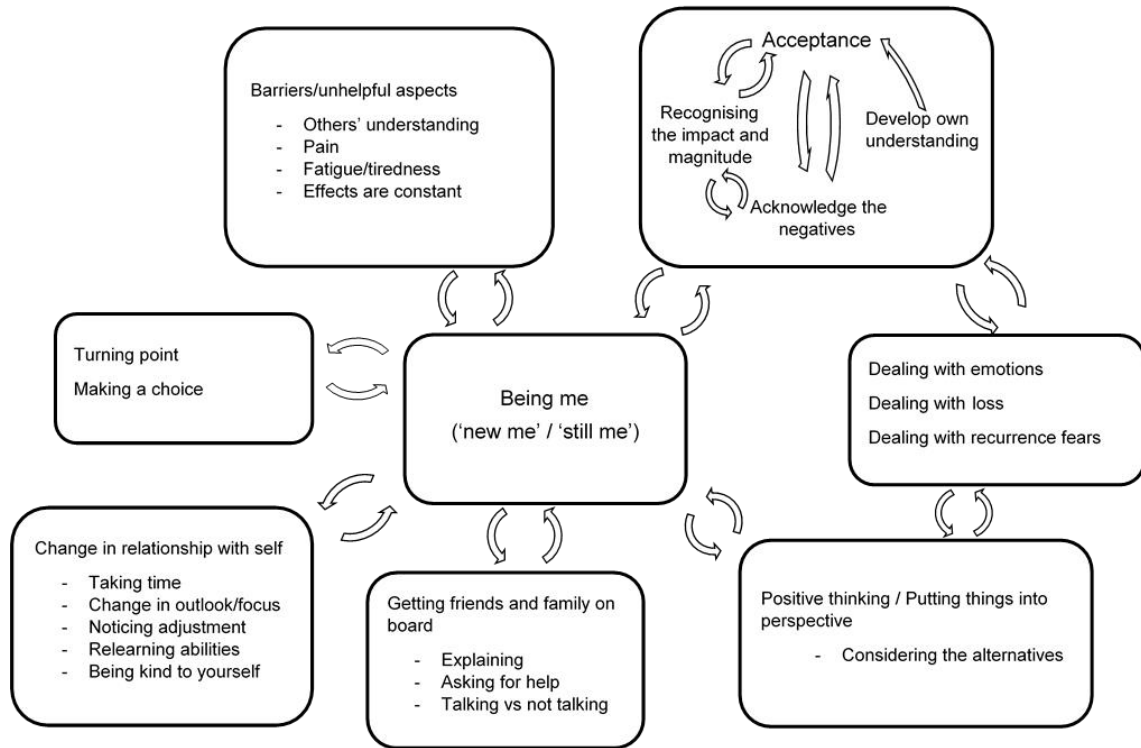
'Stages of change' (Prochaska & DiClemente, 1982) may also fit with the theory as an explanatory, overarching core category. It may be observed that the 'survive mode' is a stage of 'pre-contemplation', moving towards 'contemplation' ('making a choice') and 'action' ('acceptance', 'making changes'). The 'barriers to progress' may halt the change process, or may result in 'relapse'. Whilst this model fits, there remains a similar problem to 'fulfilling needs' as a core category – it is too broad and could encompass many more general theories.

There appears to be an element of the 'threat and loss' that is ongoing throughout the data, which may not have been encapsulated within the broader theories since they suggest that such issues can be solved and no longer considered. However, this element may instead be explained and described by a core category of 'modifying my relationship to the changes cancer brings'. This may draw out the process of patient's learning to live alongside, and with, the changes rather than continuously struggling with them. This would refer to the 'battle' essentially within the 'survive mode', and slowly lead to realising that the relationship may need to change ('making a choice'), then to more of 'living with and alongside' the changes as the patients develop more 'acceptance' and 'making changes' aspects of the theory. No matter where a patient is within the adjustment process, they still have a relationship to the changes brought on by cancer, whether it is a battle or an acceptance and a move forwards.

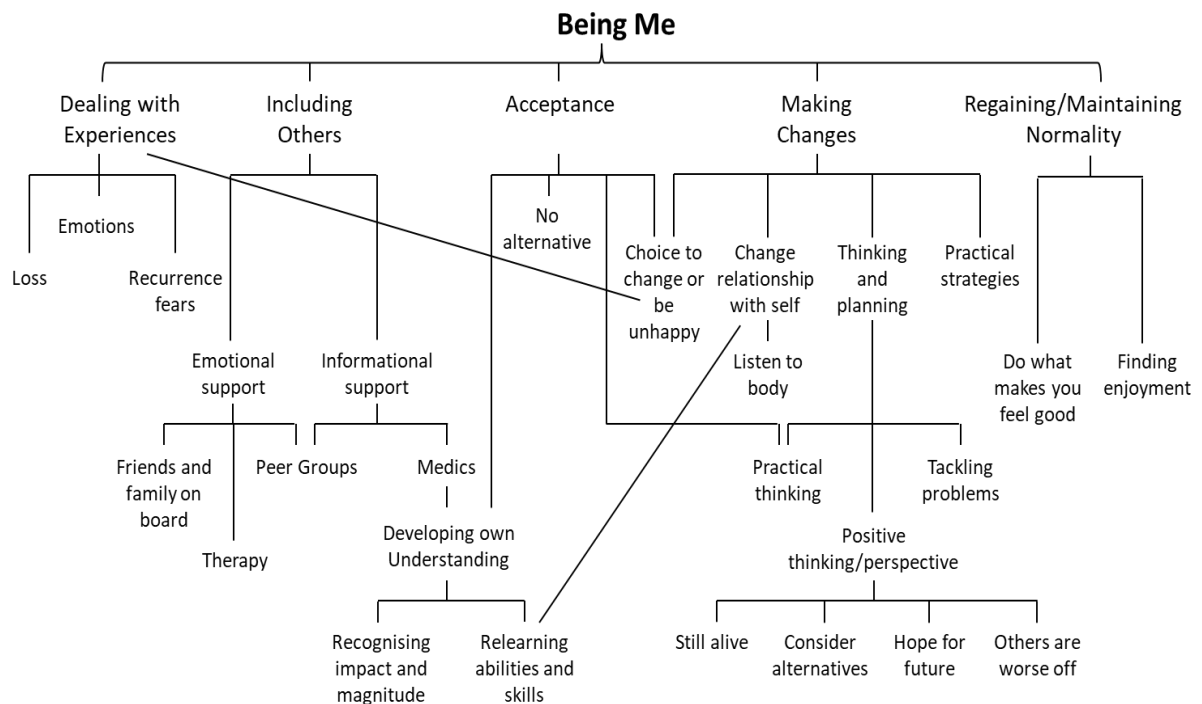
There would still be a role of needs within this core category of 'modifying my relationship to the changes cancer brings' in terms of influencing the relationship. For example, in 'survive mode', patients may only be able to attend to their basic, physiological needs; patients may not be able to entertain their psychological needs if their physiological/safety needs are not sufficiently met. This core category does appear central to all other categories/themes, and has explanatory power!

Appendix 17: Diagrammatic Theory Development

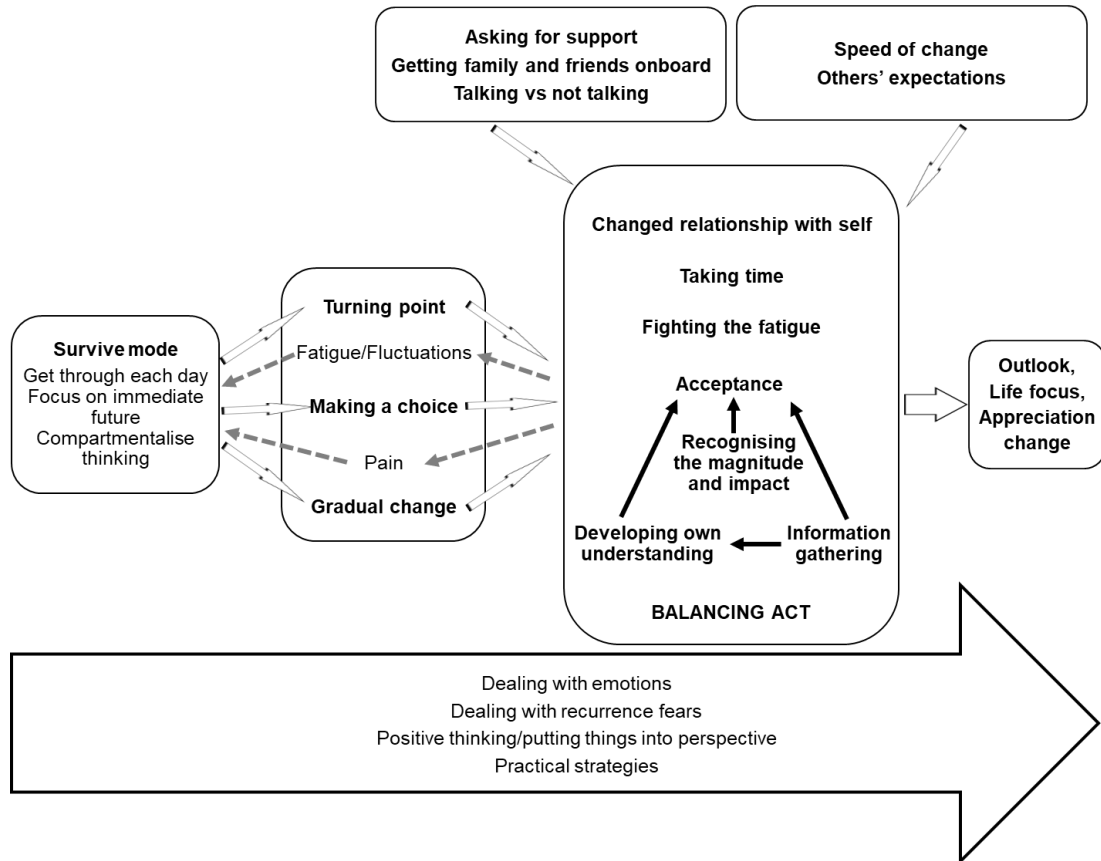
29.12.2017



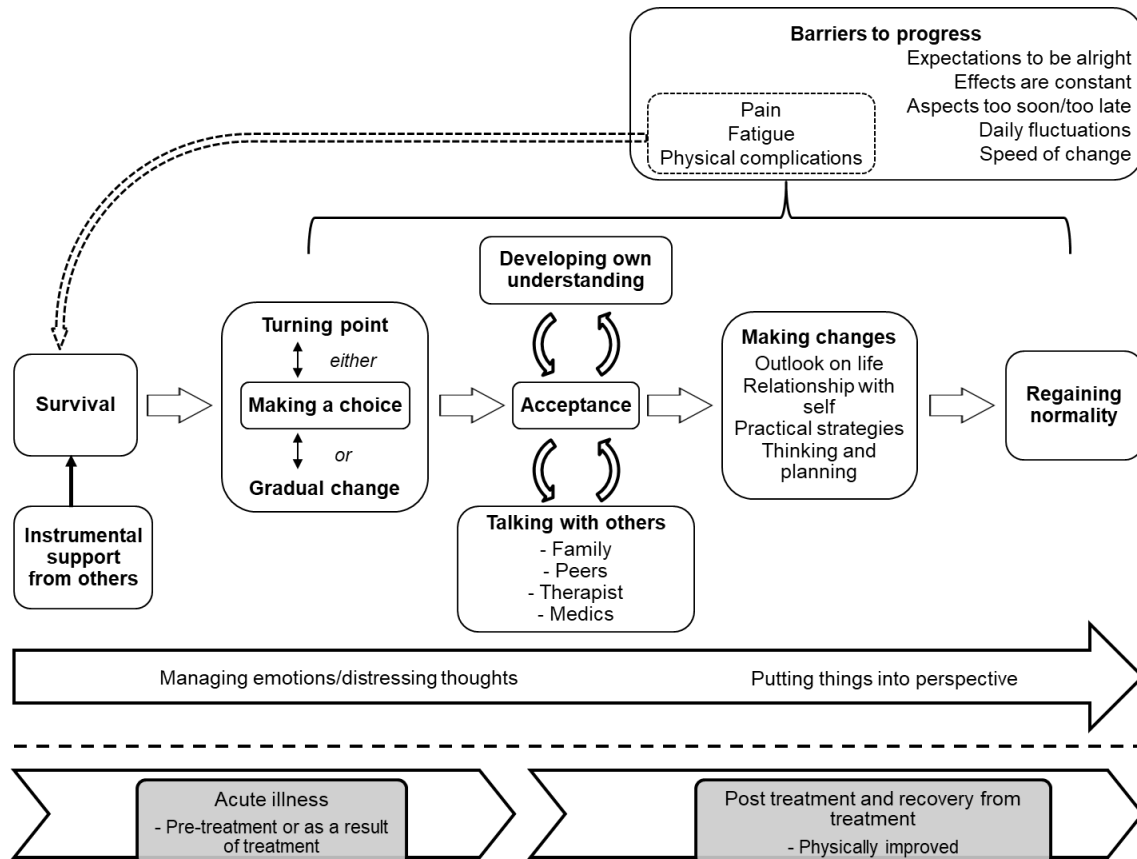
19.01.2018



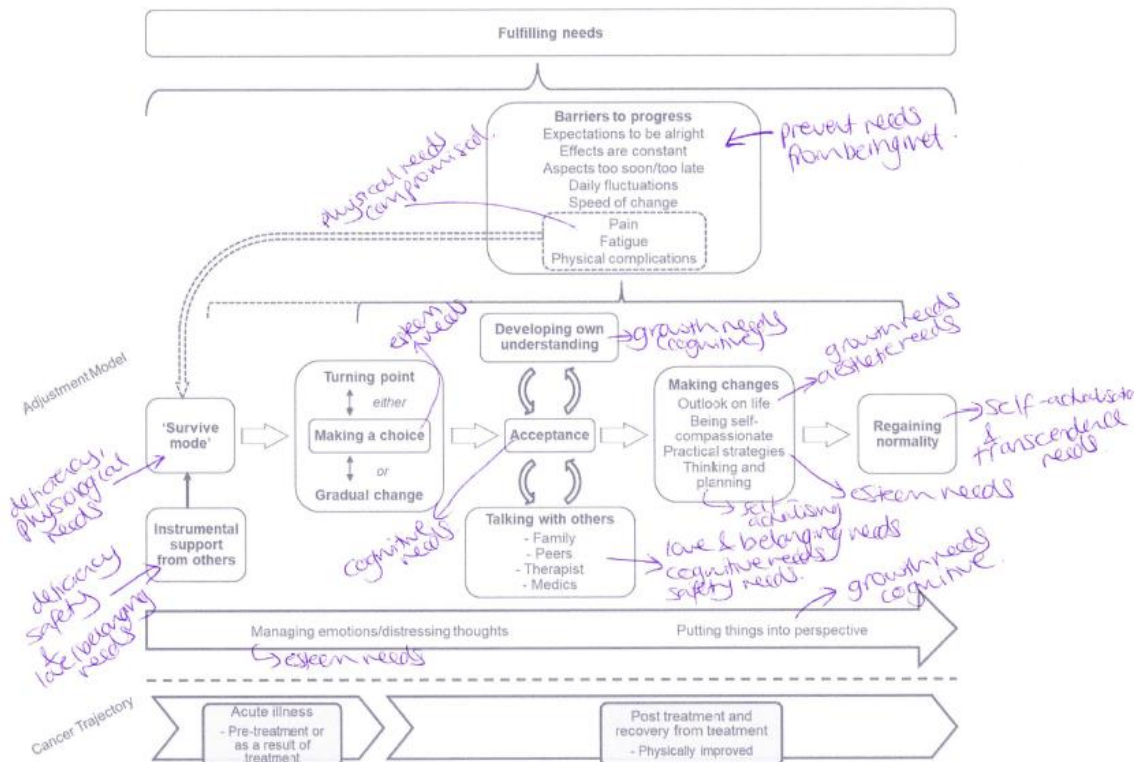
26.01.2018



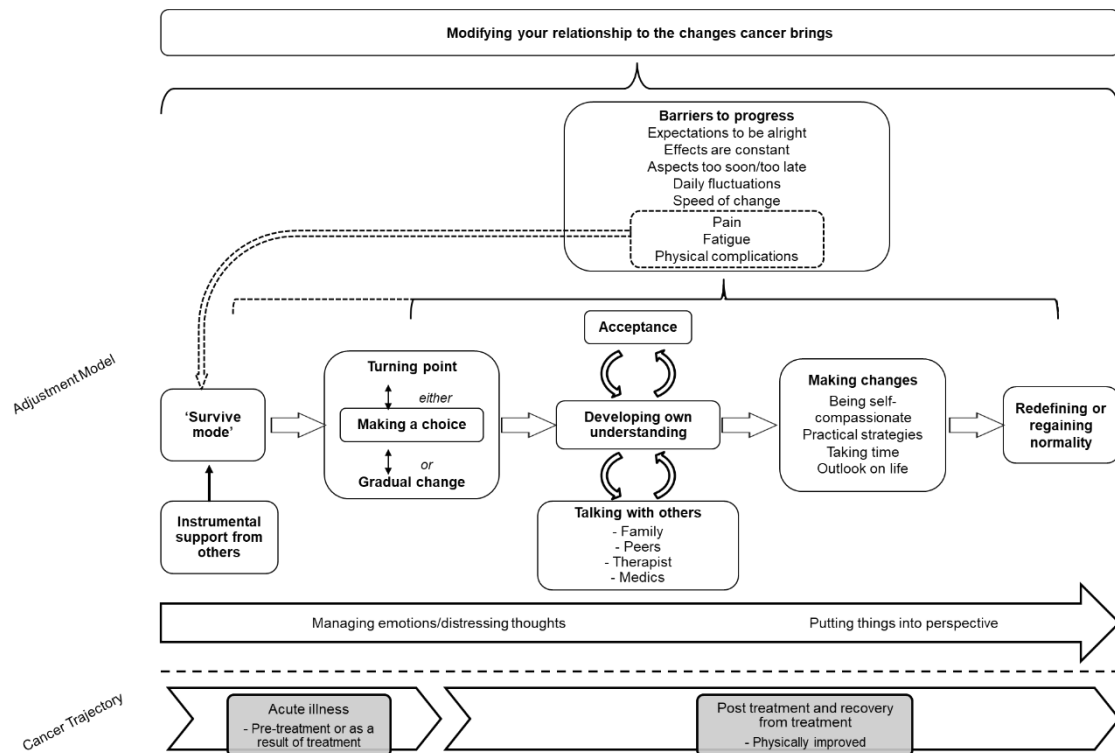
29.01.2018



14.02.2018



16.02.2018



Appendix 18: How Research Conditions were Fulfilled

Adapted from Corbin and Strauss (2008, 2015)

Criteria	Does the study satisfy the criteria?
Fit	• The model and findings were described to mostly ‘fit’ the experiences of the final three participants with whom the model was shared. These participants also endorsed the relationships between the component processes. • Feedback was gained from professionals working within the field; the findings resonated with them and they suggested minor changes which were incorporated into the final model.
Applicability	• The findings offer new insights regarding the processes patients engage in when adjusting to head and neck cancer, including how they may transition between them. This contributes new knowledge to the clinical psychology profession. • The core category meets the criteria described in Appendix 15.
Concepts	• The findings are organised into concepts which include a description of their properties and dimensions, for example, ‘making changes’ was developed in terms of ‘practical strategies’, ‘taking time’, ‘outlook on life’, and ‘developing self-compassion’.
Contextualisation of concepts	• All findings were placed in the context of the personal information participants provided about themselves (within the demographics information sheet) e.g. location and recurrence of cancer, duration since cancer treatment, provision of psychological support, and social circumstances.
Logic	• The final model encompassed a logical flow of ideas and concepts which made sense to the participants it was shared with. The ideas were

	brought together under the core process of ‘modifying your relationship to the changes cancer brings’. • The methodological decision to use grounded theory was made clear.
Depth	• The descriptions of the findings and concepts include rich descriptions, for example, participants’ different uses, definitions and understanding of ‘acceptance’. • Data collection ended when categories were deemed to have reached theoretical sufficiency.
Variation	• Contrasting data is discussed throughout the findings, identifying the different levels in which participants engaged in various processes. Negative examples are also identified, for example, two participants did not identify with the ‘survive mode’ element of the model.
Creativity	• The findings are presented in a creative visual diagram. • The findings suggest a new way of conceptualising the processes involved in psychological adjustment, and how a patient may progress through them.
Sensitivity	• Concepts were generated inductively from participant data, and emerging concepts were sampled within later interviews through the revision of the interview schedule. The interview schedule was revised three times, which allowed data collection to be grounded within participants’ experiences. • I was aware of my own assumptions regarding the data, however, the data analysis remained grounded in participant data – this was facilitated by the keeping of a reflexive diary and seeking supervision.
Use of memos	• Reflective and theoretical memos were written and used throughout the research process (see Appendix 16 for examples).

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