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The experiences of people who receive
swallow therapy following surgical
treatment of head and neck cancer.

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The research question

What are the experiences of people who receive swallow therapy following surgical treatment of head and neck cancer?

Abstract

Background

Head and neck cancer and its treatment may impact on the way a person eats drinks and speaks. These problems affect many aspects of life from practical issues such as how to swallow without choking, to challenging how an individual socialises or feels emotionally. Swallow therapy is provided by Speech and Language Therapists (SLT) to reduce the health risks associated with poor swallow function, such as pneumonia, and to improve wellbeing. A link has been identified in the literature between poor swallow function and compromised quality of life. However, there is limited information around how a swallow therapy intervention may optimally be delivered to reduce the holistic impact of swallow dysfunction. This research was initiated to explore the experiences of people who underwent swallow therapy after surgical treatment for head and neck cancer, to identify what people require from a swallow therapy intervention and to consider how it may optimally be delivered.

Method

The study used interpretive phenomenology to determine which elements of swallow therapy are beneficial and what may improve the individual's experience of receiving therapy. An interview schedule was developed with a person who had undergone head and neck cancer surgery, and piloted before use. Following this process convenience sampling was used to identify and recruit fifteen participants to undertake one to one, face to face, in depth interviews. The researcher collected and transcribed the data, then coded and categorised it into themes.

Results

Two overarching themes were identified, 'I never dreamt' and 'They look at you and they speak to you'. The first theme describes the complex reality of undergoing head and neck cancer surgery, and the enormity of the symptoms and changes people experience. The second theme covers the interactions and relationships with health care professionals following surgery.

The study makes suggestions about how people can best be prepared for what is to happen to them after surgery, how clinicians may help them adjust to their physical alterations and how to support them in the transition they experience from the person they were before their surgery to the person they will become afterwards. This includes ways to connect and help people to feel human again.

Contents

The research question	2
What are the experiences of people who receive swallow therapy following surgical treatment of head and neck cancer?	2
Abstract.....	2
Introduction	10
Background	10
Head and neck cancer	10
Treatment for head and neck cancer.....	11
Impact of surgical treatment for head and neck cancer.....	12
The meaning of food and eating	13
Experience of head and neck cancer	14
The role of the Speech and Language Therapist.....	15
Impairment based interventions	16
Psychosocial interventions.....	16
Chapter 1 Literature review	18
Method	18
Figure 1 Inclusion and exclusion	20
Table 1 Total papers identified in search.....	21
Table 2 Exclusion taxonomy example	22
Table 3 Quantitative studies of behavioural dysphagia interventions.	23
Findings	27
Swallow therapy interventions for head and neck cancer dysphagia	27
Quantitative literature	27
Systematic reviews and clinical trials.....	27
Clinical trials	29
Qualitative literature	30
The experience of dysphagia or dysphagia therapy following head and neck cancer treatment.	30
Table 3a Qualitative literature	31
Models of dysphagia therapy interventions	34
Discussion.....	34

Chapter 2 Exploration of theories and philosophies	37
Introduction	37
Method	37
Rehabilitation concepts and theories	38
The experience of diagnosis and treatment	41
Behaviour change models.....	44
Discussion.....	48
Chapter 3 Methodology	50
Aim	50
Objectives.....	50
Phenomenology	51
Alternative methodologies	51
Design.....	52
Ethics	52
Setting	55
Sampling and sample size	55
Identification of participants.....	56
Recruitment	56
Inclusion	56
Exclusion criteria	57
Participant involvement.....	57
The pilot	57
The researcher as a data collector	58
The Interview	59
Transcription	59
Analysis	59
Chapter 4 Findings	61
The participants	61
Table 4 Descriptive statistics.....	62
Themes.....	67
Table 5.....	68
I never dreamt	68
Like this for the rest of my life	69
You just do it	72

It's a journey	75
They look at you and they speak to you	78
You've got to be able to connect	79
I felt like a human being.....	82
You'll find another way	83
Give me your life into my hands and I'll look after you	85
Personal reflection	86
Conclusion.....	88
Chapter 5 Discussion.....	90
Introduction	90
Key findings	90
I never dreamt.....	91
Like this for the rest of my life	92
You just do it	92
It's a journey	94
They look at you and they speak to you	95
You've got to be able to connect	96
I felt like a human being.....	98
Give me your life into my hands and I'll look after you	99
You'll find another way	99
Implications for practice	101
I never dreamt.....	104
They look at you and they speak to you	106
Strengths and weaknesses of the study	107
Philosophical position	107
Methodology.....	108
Patient and user involvement.....	108
Timing.....	108
Rehabilitation models	109
Reflection on aims and objectives	110
Chapter 6 Conclusion	112
Core messages	112
Future directions.....	114
Appendix A-Participant Information.....	117

Appendix B- Consent form	120
Appendix C- Interview schedule	122
Appendix D- Levels of evidence	124
Appendix F- Participant demographics	126
Appendix G- Theme generation	128
Table 2- Examples of exclusion	135
Figure 1-Inclusion and exclusion	141
References	142

Definitions/ abbreviations

SLT- Speech and Language Therapist

Dysphagia - A disorder of the total process of feeding, eating, drinking and swallowing

Aspiration - Food or drink 'going the wrong way' passing below the level of the vocal cords and into the trachea.

Gastrostomy - A surgical opening through the abdomen into the stomach. A feeding device is inserted through this opening to enable a person to be fed directly in to the stomach to bypass the mouth and swallow.

Videofluoroscopy - An assessment of swallow function using moving x-rays.

Fibreoptic Endoscopic Evaluation of Swallow - An assessment of swallow using a nasendoscope to observe the larynx and oropharynx during swallow.

Declaration of Authorship

I, Camilla Dawson declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research.

The experiences of people who receive swallow therapy following surgical treatment of head and neck cancer.

I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University;
2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
3. Where I have consulted the published work of others, this is always clearly attributed;
4. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
5. I have acknowledged all main sources of help;
6. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
7. Either none of this work has been published before submission, or parts of this work have been published as: [please list references below]:

Signed:

Date: 17/12/2017

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Introduction

Background

This thesis explores the experiences of people who undergo head and neck cancer surgery and receive swallow therapy from a Speech and Language Therapist (SLT). The study discusses the realities and effects of head and neck cancer surgery from the perspective of the individual. It goes on to consider how and why specific interventions from the SLT as well as the wider team impact on a person's recovery.

In order to understand the context of this study this chapter will explore the nature of head and neck cancer, the treatments people may receive and the effects of these treatments. This is followed by discussion around the role of the SLT and the therapy they may provide.

Head and neck cancer

Between November 2012 and October 2013, 8,331 people in England and Wales were diagnosed with head and neck cancer (Health and Social Care Information Centre HSCIC 2013). It is the sixth most common cancer worldwide (Mehanna et al. 2010). Head and neck cancer is a term used to describe malignant disease affecting any region of the head and neck, excluding the brain. These areas include the oral cavity, oropharynx, nasopharynx, hypopharynx, salivary and thyroid glands. Head and neck cancer can affect the anatomy required for safe and effective swallow function, and many people present with swallowing problems at point of diagnosis (Stenson et al. 2000). Survival rates following diagnosis of head and neck cancer vary depending on the tumour cell type, primary site and presence of local or distant metastases. For example, average survival after laryngeal cancer is 73% at one year, which drops to 54% at five years (Office for National Statistics 2012). Overall, 80% of all people diagnosed with head and neck cancer are alive at a year after diagnosis. These people may be living with compromised swallow function which has a negative impact on quality of life and social functioning (Ekberg et al. 2002; Health and Social Care Information Centre 2012).

There are three principle treatment modalities for head and neck cancer, surgery, radiotherapy and chemotherapy. People who have oral cavity cancer are most likely to undergo surgery as their primary treatment, potentially followed by chemotherapy and or radiotherapy (Crombie et al. 2014). Surgical intervention involves removal of the cancer, with or without reconstruction of the affected area of the head and neck. All these treatments have challenging consequences and surgery, in particular, can often result in problems with swallow such as dysphagia and aspiration (Pauloski et al. 2004).

Treatment for head and neck cancer

Treatment for head and neck cancer is determined by the site of the disease, the size, and histopathological features, i.e. how aggressive the disease is, whether there are any distant metastases, and the overall health of the person undergoing treatment (Roland & Paleri 2011). These parameters determine whether people have surgery, with or without chemo-radiotherapy, or radiotherapy alone as the primary treatment with the intention to cure the disease.

Some people present with recurrent tumours, when they have previously undergone surgery and or chemo-radiotherapy. People who have undergone radiotherapy to the head and neck rarely undergo further radiotherapy treatment, as this risks irreversible damage to tissue. Instead, these people are more likely to be offered 'salvage' surgery, which involves operating on the recurrent or new primary tumour. This approach has inherent risks, as skin and muscle that has been previously irradiated may not heal effectively after surgery, and people may experience wound break down, fistula formation (a hole which forms between the inside of the mouth and the skin of the face or neck) and prolonged length of stay in hospital (Gokhale & Lavertu 2001).

Chemo and radiotherapy are typically provided over a number of weeks as an outpatient, whereas surgery requires an inpatient stay. The SLT may provide swallow therapy interventions to a person before, during and after either treatment modality. In the case of surgery, the SLT will attempt to improve function not only to reduce the risk of aspiration related complications, but to optimise swallow function before further treatments such as radiotherapy are commenced which have the potential to further damage swallow.

The post-surgical phase of treatment is a challenging time both physically and from a psychological perspective (Rogers et al. 2006). The physical effects of the surgery are complex and include invasive interventions. Many people undergo removal of all or some of their teeth during surgery to facilitate the reconstruction of their oral cavity and to reduce the risk of long term bone complications due to infection. People frequently require tracheostomy insertion to ensure a safe, patent airway is maintained when there is a risk of bleeding and swelling of the upper aerodigestive tract post-operatively (Halfpenny & McGurk 2000). Vacuum drains may be attached to either side of the neck to drain fluid after neck dissection. A neck dissection is carried out to remove lymph glands in the neck which may contain cancerous deposits (Roland & Paleri 2011).

When a cancer is removed from the head and neck, tissue is required to reconstruct the space left from the surgery, this is called a 'flap'. This tissue is taken from an alternative site in the body such as skin and muscle from the forearm (a radial forearm free flap), skin, muscle and bone from the lower leg (fibula flap), skin bone and muscle from the shoulder blade (scapula flap), skin and muscle

from the thigh (antero-lateral thigh flap), or skin muscle and bone from the hip (deep circumflex iliac artery flap) to reconstruct their oral cavity. When people undergo this type of operation they require careful observation for at least twenty four hours on an intensive care unit (Roland & Paleri 2011) due to the risks of post-operative bleeding and monitoring of the reconstructed site.

The physical effects of this surgery are complex and impact on the individual in a number of ways including changing the way a person can eat and drink. This particular problem can compromise many components of life including how a person socialises and engages in important parts of what being human means. The following sections explore this in detail.

Impact of surgical treatment for head and neck cancer

In medical science 'dysphagia' is a term used to describe a disorder of the total process of feeding, eating, drinking and swallowing (RCSLT 2005). Swallow problems may be characterised by changes to the strength, coordination and overall safety of swallow, causing coughing before, during or after swallow, eyes to water, pain in the chest, oxygen saturation levels to fall, food getting stuck during swallow, and choking (Manikantan et al. 2009). Surgical treatment for head and neck cancer may result in dysphagia as a result of changes to structures of the oral cavity and pharynx, which are required for safe and effective swallowing (Pauloski et al. 2004). This may also result in aspiration, where food or fluid passes below the level of the vocal cords and into the lungs.

Aspiration is a symptom of dysphagia which impacts negatively on respiratory function, hydration and nutrition, as people may not be able to safely consume enough food or fluid to meet their nutritional requirements. Aspiration can cause acute chest sepsis and if untreated can lead to pneumonia and death. People who aspirate have been shown to be up to thirteen times more likely to develop pneumonia than people with normal swallow function (Pikus et al. 2003). Alongside risks to the health of the individual, aspiration pneumonia has economic implications, such as the cost to health care services as a result of admissions to hospital and prolonged bed stay days (Niederman et al. 1998).

In the initial post-surgical phase when the tracheostomy is in place, it may not be possible to talk or speak. This can be very challenging and distressing during interactions such as surgical ward rounds, reducing the individual's ability to engage with the health care team to discuss problems they may have. In this instance people may use a pen and paper to communicate. People's appearances may also change dramatically following head and neck cancer surgery, especially in the early post-operative phase. Disfigurement severity has been shown to correlate with the degree of dysfunction a person experiences, where greater levels of disfigurement have been observed in people with high

levels of self-reported dysfunction specifically related to chewing, dribbling saliva, and articulating (Katz et al. 2000).

People may experience anxiety, fear and embarrassment caused by coughing or choking during meals; these symptoms may then influence whether individuals feel able to engage in social occasions such as meeting with friends or family, potentially leading to disengagement and isolation (Ekberg et al. 2002). Eating and drinking may form a significant part of social, religious and cultural occasions, or enable people to make choices and receive physical comfort (McQuestion et al. 2011).

The meaning of food and eating

Food, drink and eating have more complex meanings and impact than simply nutritional value.

Anthropologists have studied what food and eating means since the nineteenth century and have identified ways in which food demonstrates and influences social and cultural processes, religion, and the social construction of memory (Mintz & Du Bois 2002). In 'The Anthropology of Food and Eating', Mintz and Du Bois (2002) explain that "Next to breathing, eating is perhaps the most essential of all human activities, and one with which much of social life is entwined" (page 102).

Sociologists have also described the cultural significance of eating and drinking. They describe how individuals make deliberate choices about what food they eat and where they eat it, which helps people to engage with cultural and social norms (Murcott 1982). Murcott (1982) describes social rules about table manners and the ways people present food, and invokes work by Claude Levi-Strauss which suggests that the place of eating and drinking and its rituals enable people to distinguish themselves from savages and animals, by demonstrating they are civilised and human (Levi-Strauss et al. 1969). Whilst this is a very specific reflection on the social and cultural norms associated with eating and drinking, it highlights the impact and influence of food beyond nutritional value.

The sociological and anthropological position on eating and drinking gives context to this study, which seeks to explore the experiences of people who have had surgery for cancer and may have difficulties with eating and drinking. When a person is unable to eat and drink, they may be unable to engage in social and cultural norms, to maintain social rules, or to practise religious rituals. Therefore, what it means to people not to be able to eat and drink in these circumstances requires exploration in order to improve understanding of how people feel and what support they require. This perspective moves beyond the biomedical paradigm, which tends to view an inability to eat and drink as a symptom of disease, and sets it within a framework which recognises these activities as a cornerstone of human existence.

Experience of head and neck cancer

The experiences of head and neck cancer and its treatment are complex. Broadly these may be broken down into physical, psychological and psychosocial experiences. Physical effects have been identified in several research studies, and include dry mouth, taste changes, dysphagia, communication compromise, neck and shoulder dysfunction, generalised oral cavity pain (Murphy et al. 2007) weight loss, voice changes, nausea, lethargy, and sleep disturbance (Rose-Ped et al. 2002). A relationship between disfigurement and dysfunction has also been noted where physical dysfunction and disfigurement impacts on a person's psychological wellbeing (Rhoten et al. 2014), and these experiences should not be viewed or treated in isolation

Other diverse and complex matters have also been identified in the study of people who undergo treatment of head and neck cancer. Donovan and Glackin (2012) carried out a literature review to explore people's experiences of radiotherapy for treatment of head and neck cancer, as they estimate that 60% of people will receive radiotherapy at some point in their disease trajectory. Themes identified included psychological symptoms, such as dread and apprehension of treatment beginning, as well as distress and uncertainty about waiting for test results and treatment plans. The review also uncovered themes about change in a person's perception of themselves alongside a heightened awareness and concern about death (Donovan & Glackin 2012).

A qualitative study by Parker et al. (2014) explored the experiences of people who underwent surgery for treatment of head and neck cancer (not including information on their swallow intervention). This research found many challenging psychological experiences, as people felt inadequately prepared for treatment, which resulted in participants feeling frightened, alone and ignored. These problems related to people's sense of security and control, which had been compromised. Some people reported feeling betrayed, as their experience of extreme post-operative pain was unexpected, and hadn't been identified in the pre-operative phase by health care professionals. Participants reported that had they known the intensity of pain, and altered function that they would face, they may not have chosen to undergo the operation. People felt betrayed as they did not believe they had been given the option of 'doing nothing' and not having the operation, which they may have preferred (Parker et al. 2014). People were shocked and were not expecting their diagnosis of head and neck cancer and this had a profound impact on their psychological wellbeing, leading to fear and speculation about forthcoming treatments (Parker et al. 2014). These emotions threatened a person's sense of emotional resilience and coping. The impact of depression and self-pity were of note as these seemed to relate to report of changed meaning of life following diagnosis and treatment (Parker et al. 2014).

The psychosocial changes to life as a result of swallowing problems have been explored, with specific reference to relational issues. Patterson et al. (2013) identified loss of togetherness at mealtimes alongside difficulties with managing and engaging with social occasions, such as holidays or weddings. Schaller et al. (2014) found that people with head and neck cancer needed to make changes to their activities of daily life due to illness and fatigue, which had an impact on, and compromised the individual's family role and identity. Returning to work and maintaining a job was also noted as a challenge. People felt like a burden to their family due to financial shortfalls as a result of unemployment following diagnosis and treatment (Parker et al. 2014).

People's experiences of head and neck cancer and its treatments are complex. The symptoms people experience impact on social, emotional and physical component of life, and are likely to contextualise swallow therapy interventions. However, there is no evidence to suggest that these problems are acknowledged or woven into swallow therapy interventions, or indeed how recognition of their existence may be embedded within interventions to improve outcomes.

The role of the Speech and Language Therapist

The SLT assesses and provides therapy to people from the point of diagnosis of head and neck cancer before, during and after surgery and or chemo-radiotherapy and beyond treatment. Goals of Speech and Language Therapy interventions are varied, and may focus on improving speech, language or swallow function, developing and adapting to changes in identity, enhancing function, promoting health, or identifying barriers and facilitating social participation (Bray et al. 1999). In the field of dysphagia following head and neck cancer, the predominant form of therapeutic intervention is likely to be impairment based (Govender et al. 2013) to manage the medical risks associated with dysphagia. However, the SLT may provide various combinations of both impairment targeted intervention and psychosocial support. The term 'impairment' refers to therapy to remediate a specific issue which impacts on function.

There is very little information available in the literature to determine what impairment or psychosocial support from the SLT may look like, or how interventions may be delivered to achieve optimal outcomes. There are no documented swallow therapy models for the SLT working with people with head and neck cancer, and there is great variability between speech and language therapy interventions in both the UK (Roe et al. 2012) and America (Krisciunas et al. 2012). This is problematic, as a growing body of evidence demonstrates the life altering impact of head and neck cancer and its treatment (Ferlito et al. 2003) yet there is no available agreed standard or optimal intervention approach regarding rehabilitation.

Impairment based interventions

Impairment based interventions may begin with the SLT assessing swallow, by using observation of the person eating and drinking various consistencies of food and fluids. If there are signs or symptoms of dysphagia, such as coughing before during or after swallow, oxygen saturation levels falling, or pain or discomfort reported, the SLT may suggest ways to manage the swallow impairment.

Techniques to improve swallow competence may also include postural changes and swallow manoeuvres by directing food or drink via intact musculature rather than anatomy that may have been altered by disease or surgery (McCabe et al. 2009). Manoeuvres include, but are not limited to, a chin tuck during swallow, a super-supraglottic swallow which involves breath holding whilst initiating an effortful swallow, and the Mendelsohn manoeuvre, an intervention which enables a person to use a sequential swallow of fluid whilst the larynx remains in an elevated position. Postural changes can also slow down the transit of food or fluid bolus, enabling the person to adopt a position which protects the airway during swallow, preventing aspiration (Logemann et al. 2008). In addition, solid food may be pureed or made soft, making swallow more comfortable and reducing the risk of choking or pain on swallow.

The SLT may prescribe postural modifications and will make changes as required during the rehabilitation intervention. Targeted exercise regimens may also be used to optimise muscles required in specific phases of swallow (Carnaby-Mann et al. 2012) to improve the safety and efficiency of the swallow process. The SLT may also facilitate conversation and discussion between the person who has undergone treatment and the surgical team, using high level communication skills to interpret compromised speech, however little is understood about the nature of this component of the intervention or how it is delivered.

Psychosocial interventions

Clinical nurse specialists, head and neck counsellors and psychologists work collaboratively to improve psychosocial function. Alongside these professionals, it is recognised that the SLT will provide specific counselling and holistic support to manage the psychological effects of dysphagia (RCSLT 2005) as a result of their training in psychology at an undergraduate level, which forms a significant part of the curriculum for many Speech and Language Therapy training courses in the UK. Post graduate courses are also available which enable the SLT to use Solution Focussed Therapy, or Cognitive Behavioural Therapy for example, however this training is not universally attended and many therapists are likely to rely on undergraduate training and experience to influence their interventions (Krisciunas et al. 2012).

The nature of the counselling and psychosocial support which is provided by the SLT is poorly defined. This is partly because individual Speech and Language Therapists are likely to provide a diverse and varied quantity and quality of this type of intervention, making it challenging to study. It is also seldom recognised or described in studies of swallow therapy or swallow outcomes. Typically studies about swallow outcome explore the type of oncological or surgical intervention and the resultant physical compromise. The studies available rarely capture the psychosocial support the person may have received from the SLT.

Enderby (2012) explains that whilst it is challenging to demonstrate the impact of interventions on physical components such as function, it is even more difficult to demonstrate the value of therapy on psychosocial wellbeing and participation, thus very few studies explore this issue. It is likely that problems with heterogeneous samples, inadequate underpowered sample sizes, few psychosocial outcome measures and limited numbers of research-active Speech and Language Therapists may contribute to this issue. However, more complex philosophical matters may also influence this matter. The philosophical position of much of the research available around swallow outcomes exists within a positivist paradigm. Reports of cause and degree of dysfunction are most readily published in research journals, whilst very few examples of qualitative studies around a person's experience of dysphagia are available.

In order to understand how swallow therapy could be developed to improve quality of life outcomes, research needs to move beyond simply identifying the relationship between poor swallow and compromised quality of life. Rather, individual and experiential facets of swallow therapy interventions may be more effectively captured within an interpretivist paradigm that may expose how and why people respond to various dysphagia treatments. deBronkart (2015) describes the value of patient participation and engagement in healthcare, and suggests that it is not possible for medicine to achieve its full potential without the contribution and voice of thinking patients.

In order to address and understand the experiential facets of dysphagia there is a need for research to explore what the experience of the post-surgical phase may be, and how swallow interventions may be provided during this time to improve the holistic outcomes of people who undergo surgery.

Chapter 1 Literature review

The volume of literature about swallow function and head and neck cancer has developed over the past forty years. As an overview a publication by date search on Pub Med using the term ‘dysphagia and head and neck cancer’ demonstrated that in 1980 there were 45 publications identified using the search terms, which grew to 330 in 2015. Many of these studies explore the incidence or severity of dysphagia, rather than the swallow therapy itself, and even less the perceptions of the person receiving swallow therapy following head and neck cancer surgery. In order to gather a detailed understanding about these particular issues a systematic literature review was undertaken.

The objectives of this literature review were to identify:

1. The extent of the literature concerning swallow therapy interventions from an SLT for people who had undergone head and neck cancer treatment, with specific reference to surgery.
2. Whether any literature explored a person’s experience of dysphagia or dysphagia therapy following head and neck cancer treatment.
3. Whether any models of dysphagia therapy interventions for people with head and neck cancer existed.

Method

A literature review was undertaken to explore the evidence base. Medline, EMBase, EBSCOhost, Web of Science, CINAHL, the Cochrane Library, NICE (National Institute of Health and Clinical Excellence) and the NHS centre for Reviews and dissemination were used in the literature search. No time frame limits were imposed on the search criteria as initial searches indicated limited information around each topic, so all pertinent research was included in the review. Hand searching, exploring reference lists from similar research studies, reading contents lists from relevant journals, reading comments and editorials alongside searching in dysphagia therapy textbooks also formed part of the search.

The search terms used were ‘swallow therapy’ ‘dysphagia therapy’ ‘deglutition therapy’. Deglutition therapy was added after searching PubMed MeSH terms for ‘dysphagia’. The terms were combined using the Boolean ‘AND’; the ‘therapy’ key word used the Boolean ‘OR’ as ‘therapy OR treatment or intervention’. ‘Head and neck cancer’ was also used alongside the search term, to limit the results to studies of the target population, to avoid results which included different populations such as people with stroke, or paediatric dysphagia interventions which require specific rehabilitation approaches due to the nature of the problem. Similar search terms have been published in a recent systematic

review protocol which explores dysphagia interventions in head and neck cancer (Govender et al. 2015).

Inclusion criteria:

- 1) Study population includes people with dysphagia following head and neck cancer
- 2) Study of a behavioural intervention to rehabilitate dysphagia (a behavioural intervention is defined as a specific intervention to change or modify a behaviour relating to the management of a person's dysphagia)
- 3) English language

Exclusion criteria:

- 1) Investigations of the incidence of dysphagia after head and neck cancer
- 2) Investigations only of instrumental interventions to rehabilitate or assess dysphagia (i.e. electrical stimulation or experiments of video fluoroscopy sensitivity)
- 3) Investigations of experiences only of head and neck cancer as the review sought to identify dysphagia interventions
- 4) Investigations of dysphagia outcome measures

In total 3962 papers were identified (See table 1). In the first instance, due to the volume of literature, the titles were assessed for inclusion. Papers were sorted into categories of 'inclusion' or 'exclusion' and categorised for their reason of exclusion, an example is presented in table 2. If there was any ambiguity around whether the paper should be excluded, the paper was included and assessed in more detail at the next phase. This process reduced the numbers of papers for review to 43. The abstracts and or full text of these 43 papers were then read by the researcher. The majority of papers were excluded as they reported on swallow outcomes as a result of oncological interventions, without exploring a speech and language therapy intervention (see figure 1). Twenty papers were included in the final review and the quantitative designs are detailed in table 3.

Figure 1 Inclusion and exclusion

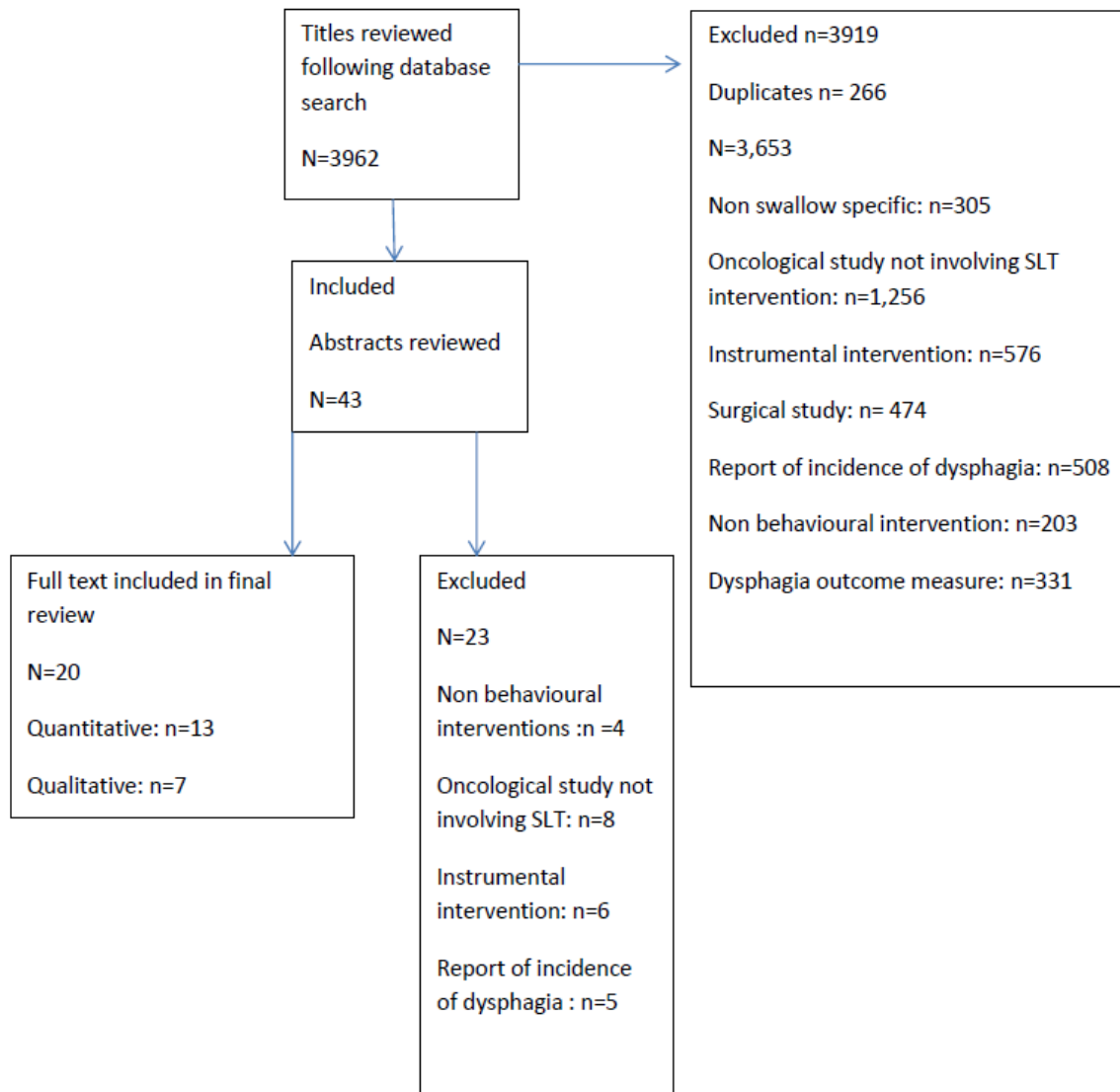


Table 1 Total papers identified in search

Platform	Search term	Result	Included	Excluded
Medline (EBSCOhost)	swallow AND (therapy or treatment or intervention) AND (head and neck cancer)	131	6	125
	dysphagia AND (therapy or treatment or intervention AND (head and neck cancer)	128	4	124
	deglutition AND (therapy or treatment or intervention) AND head and neck cancer	72	1	71
Medline (PubMed)	swallow AND (therapy or treatment or intervention) AND (head and neck cancer)	752	4	748
	dysphagia AND (therapy or treatment or intervention) AND (head and neck cancer)	760	9	751
	deglutition AND (therapy or treatment or intervention) AND (head and neck cancer)	727	1	726
EMBASE (Ovid)	swallow AND (therapy or treatment or intervention) AND (head and neck cancer)	4	0	4
	dysphagia AND (therapy or treatment or intervention) AND (head and neck cancer)	52	4	48
	deglutition AND (therapy or treatment or intervention) AND (head and neck cancer)	0	0	0
Web of science	swallow AND (therapy or treatment or intervention) AND (head and neck cancer)	33	7	26
	dysphagia AND (therapy or treatment or intervention) AND (head and neck cancer)	38	2	36
	deglutition AND (therapy or treatment or intervention) AND (head and neck cancer)	1	0	1
CINAHL	swallow AND (therapy or treatment or intervention) AND (head and neck cancer)	48	2	46
	dysphagia AND (therapy or treatment or intervention) AND (head and neck cancer)	142	0	142
	deglutition AND (therapy or treatment or intervention) AND (head and neck cancer)	203	0	203
Cochrane Library	swallow AND (therapy or treatment or intervention) AND (head and neck cancer)	289	3	286
	dysphagia AND (therapy or treatment or intervention) AND (head and neck cancer)	289	0	289
	deglutition AND (therapy or treatment or intervention) AND (head and neck cancer)	293	0	293
NICE	swallow AND (therapy or treatment or intervention) AND (head and neck cancer)	0	0	0
	dysphagia AND (therapy or treatment or intervention) AND (head and neck cancer)	0	0	0
	deglutition AND (therapy or treatment or intervention) AND (head and neck cancer)	0	0	0
Total		3962	43	3919

Table 2 Exclusion taxonomy example

Name of paper	Reason for exclusion
Pharyngoesophageal stricture after treatment for head and neck cancer.	Oncology only not speech and swallow therapy specific
Dental rehabilitation after surgery for oral cancer	Non swallow specific
Management of oropharyngeal Dysphagia in laryngeal and hypopharyngeal cancer.	Surgical study
Dynamic MRI analysis of tumor and organ motion during rest and deglutition and margin assessment for radiotherapy of head-and-neck cancer	Non swallow specific
Objective assessment of swallowing function after definitive concurrent (chemo)radiotherapy in patients with head and neck cancer	Instrumental intervention
Priorities for the head and neck cancer patient, their companion and members of the multidisciplinary team and decision regret	Non behavioural
Swallowing function following postchemoradiotherapy neck dissection: review of findings and analysis of contributing factors	Incidence of dysphagia
Risk of aspiration following radiation for non-nasopharyngeal head and neck cancer.	Oncology only not speech and swallow therapy specific
History of voice rehabilitation following laryngectomy.	Non swallow specific
Phase II trial of the histone deacetylase inhibitor vorinostat (Zolinza, suberoylanilide hydroxamic acid, SAHA) in patients with recurrent and/or metastatic head and neck cancer.	Oncology only not speech and swallow therapy specific
Reliability and validity of the Vanderbilt Head and Neck Symptom Survey: a tool to assess symptom burden in patients treated with chemoradiation	Dysphagia outcome measure

Table 3 Quantitative studies of behavioural dysphagia interventions.

Reference	Country	Study design	Population	Measure	Intervention	Reported outcome
Blyth et al. (2015) Level 1 evidence	Australia	Systematic review of 7 articles. Behavioural interventions for speech and/or swallowing dysfunction following partial oral tongue surgery.	N=133 All included studies used sample sizes >50. Three studies single case reports, 4 studies explored speech not swallow.	Video fluoroscopy, Nasendoscopy, Surface electromyography, MD Anderson Dysphagia Inventory.	Behavioural exercises including: Mendelsohn and effortful swallow, postural modification, tongue and jaw range of movement exercises.	Reduction of aspiration and pharyngeal residue on VFS, Removal of NG feeding tube Increased muscular peak on SEMG, Return to full oral intake for 3/6 oral tongue patients, Improvement in MD Anderson Dysphagia scores from pre to post in experimental group.
Carnaby-Mann and Crary (2010) Level 4 evidence	USA	Case-control 18 Participants had undergone treatment for head and neck cancer (no detail of previous treatment type) 4 had neurological injury.	n=24 case=8 control=16	Functional oral intake scores, presence of tube feeding, video fluoroscopy.	Behavioural intervention Intensive muscle strengthening protocol	Dysphagia reduced by 69% in case group, both approaches resulted in functional improvements.
Carnaby-Mann et al. (2012) Level 1 evidence	USA	RCT Participants underwent radiotherapy treatment for head and neck cancer.	n = 58 Case = 20 Sham = 18 Control = 20	Muscle size and composition measured by MRI Functional swallowing ability Mouth opening Chemosensory function Salivation Nutritional status Occurrence of dysphagia-related complications	Behavioural exercise Prophylactic exercise, jaw strengthening, effortful swallow, tongue exercise.	Prophylactic exercise intervention group, improved preservation in T2 MRI scores, functional swallowing, mouth opening, taste and salivation. Mean standardized difference (t2 value mylohyoid)a Cohen's d = -0.36 (95 % CI -0.098 to 0.26)

Reference	Country	Study design	Population	Measure	Intervention	Reported outcome
Denk et al. (1997) Level 4 evidence	Austria	Case series, pre and post. Participants underwent surgical treatment for head and neck cancer.	n=32	ENT examination, video-endoscopic swallowing study , video fluoroscopy. Recorded at time points before and after functional swallowing therapy.	Behavioural exercise Ice stimulation of swallow reflex, lip tongue and swallow exercises, posture and diet modification	Successful rehabilitation for 75% of participants who regained full oral intake after surgery.
Hutcheson et al. (2013) Level 4 evidence	USA	Case series Participants all underwent radiotherapy or Chemoradiation.	n= 497	Length of gastrostomy dependence; adherence to swallow exercises, diet taken via mouth.	Behavioural exercises Hyolaryngeal excursion, airway protection, tongue base retraction, jaw stretch, yawn, gargle, and effortful swallows.	58% participants reported adherence to the swallow exercises. Participants who managed some diet through Chemo-radiotherapy or radiotherapy maintained a normal diet through long term survivorship (around 22 months). 65% who didn't eat or exercise also returned to a regular diet after treatment.
Kotz et al. (2012) Level 3 evidence	USA	Case control Participants underwent radiotherapy treatment for head and neck cancer.	n = 26 Case = 13 Control = 13	Functional oral intake score, performance status scale, feeding tube placement Recorded at time points, baseline, immediately after radiotherapy, and at 3, 6, 9, and 12 months after radiotherapy.	Behavioural exercise Effortful Swallow, tongue base retraction exercises, effortful swallow technique, and the Mendelsohn manoeuvre.	No significant differences between groups immediately after radiotherapy or at 9 or 12 months. Improved function was noted at 3 (p=0.03) and 6 month assessments (p=0.009) in the case group.
Lazarus et al. (2014) Level 3 evidence	USA	Randomised clinical trial Participants underwent radiotherapy with or without chemotherapy.	n=23 case=11 control=12	QOL outcome measures, measures of tongue strength, clinician rated measure of swallow efficiency	Behavioural exercise Tongue strengthening exercises	No differences in outcomes between groups.

Reference	Country	Study design	Population	Measure	Intervention	Reported outcome
Logemann et al. (2009) Level 3 evidence	USA	Randomised clinical trial Participants underwent surgery and or chemoradiotherapy or presented with stroke.	n=19 case=8 control=11	Video fluoroscopy	Behavioural exercise Shaker exercise-based on the upward and forward movement of the hyolaryngeal Structures.	Greater reduction in post-swallow aspiration in the case compared with control group (p = 0.028).
McCabe et al. (2009) Level 1 evidence	USA	Systematic review Behavioural interventions for swallow therapy following cancer treatment.	N=60 31/60 with head and neck cancer, 6/31 surgery alone, 1/31 chemotherapy alone 7/31 radiation alone, 7/31 surgery and radiation therapy.	Video fluoroscopy, manometry to measure swallow pressures.	Behavioural exercise including: Mendelsohn and effortful swallow, and postural modifications.	Reduced amount of residue within oropharynx post swallow, improved duration and pressure of swallow musculature, improved functional oral intake scores.
Nguyen et al. (2007) Level 4 evidence	USA	Case series, pre and post. Participants underwent chemoradiation (n=24) or post-operative radiation therapy (n=17).	n=41	Modified barium swallow	Behavioural exercise Diet modifications, Swallow manoeuvres	13 patients (32%) demonstrated improvement in dysphagia severity. 7/13 received chemoradiation, 6/13 received post-operative radiotherapy.
van der Molen et al. (2014) Level 3 evidence	Netherlands	Clinical trial Participants underwent radiotherapy treatment for head and neck cancer	n=29 Case=15 Control=14	Videofluoroscopy, study-specific questionnaires post treatment (10 weeks, 1 year, and 2 years)	Behavioural exercise Gargling, jaw stretching, laryngeal elevation exercises, tongue base exercises.	In first year post chemo radiotherapy all treatment symptoms reduced except xerostomia (59 %). Only significant difference was weight gain at 2 years in experimental group (p = 0.002).
Zhen et al.	China	Non-randomized	n=46	MD Anderson Dysphagia	Behavioural exercise	Improved global MD Anderson

(2012) Level 3 evidence		controlled trial Participants underwent surgical treatment for head and neck cancer.	case=23 control: 23	Inventory	Diet modification; environmental arrangement; positioning (including chin-down and head rotation); compensatory swallowing strategies, including the Mendelsohn manoeuvre (sequential swallow) and effortful swallow.	Dysphagia Inventory scores in case group (p=0.01)
Reference	Country	Study design	Population	Measure	Intervention	Reported outcome
Zuydam et al. (2000) Level 4 evidence	UK	Case series Participants all underwent surgery	n=13	Video fluoroscopy	Behavioural exercise Chin tuck and effortful swallow.	Descriptive statistics used, due to small sample size. Strategies effective in 50% of people who aspirated, most effective between one and six months post-surgery.

Findings

Swallow therapy interventions for head and neck cancer dysphagia

The search identified a limited body of literature regarding what kind of swallow therapy interventions are provided to people with dysphagia as a result of head and neck cancer, or what the effect of these interventions may be. Very few papers explored swallow therapy interventions targeted specifically at the post-surgical phase and no papers explored experiences of swallow therapy interventions after surgery. There was a small volume of literature which described the experience of dysphagia or dysphagia therapy services following head and neck cancer, but this focused on people who had undergone chemo or radiotherapy treatment rather than surgery. There were no models of dysphagia therapy noted in the literature search.

The Oxford Levels of Evidence (OCEBM 2011) were used to classify the studies. Studies were categorised from one to five, level one representing the highest quality of evidence from meta-analysis or systematic review, and level five representing expert opinion that lacked robust scientific underpinning (See appendix D). Three level one studies were identified in this search, however no meta-analyses have been undertaken to identify optimal swallow therapy interventions for people who have undergone treatment for head and neck cancer.

Quantitative literature

Systematic reviews and clinical trials

This literature review identified only two systematic reviews which explored interventions to improve swallow function. These reviews identified numerous and diverse range of outcome measures used to denote the success of an intervention (see Table 3). This makes it difficult to compare study outcomes meaningfully when these are not homogeneous. The systematic reviews reported on therapeutic interventions which ranged from swallow and or speech rehabilitation following partial tongue surgery (Blyth et al. 2015), to specific manoeuvres and postures used to improve swallow competence (McCabe et al. 2009). Six studies included in the Blyth et al. (2015) systematic review were all considered level four or five evidence. The majority of these studies had poor comparator groups and had poor statistical reporting so it was not possible to determine definitive effects of the interventions. The authors (McCabe et al. 2009; Blyth et al. 2015) recommended researchers conduct more carefully controlled experimental designs, to reduce the heterogeneity in treatment methods tested, and to improve statistical reporting with adequate powering.

One randomised controlled trial, (Carnaby-Mann et al. 2012) and six clinical trials (Denk et al. 1997; Logemann et al. 2009; Kotz et al. 2012; Zhen et al. 2012; Lazarus et al. 2014; van der Molen et al. 2014) were identified in the literature review. These were the only published trials that explored behavioural swallow therapy interventions for people who had undergone treatment for head and neck cancer. The clinical trials, all level three evidence, were studies of various different approaches to behavioural swallow rehabilitation after combinations of surgery and or chemo-radiotherapy (see table 3). The interventions tested included exercise to improve tongue base function and to reduce aspiration following head and neck cancer (Logemann et al. 2009), the effects of jaw stretching technologies in addition to standard swallow exercises (van der Molen et al. 2014), the impact of postural adaptations, diet modifications and swallow techniques following tongue surgery (Denk et al. 1997; Zhen et al. 2012).

Some of the trials identified positive outcomes from exercise interventions. In the Logemann et al. (2009) study the case (n=8) and control (n=11) group both demonstrated improvements in aspiration severity, but statistically significant improvements were only seen in the experimental group (that used a specific swallow manoeuvre to improve function)(p = 0.028). The van der Molen et al. (2014) study of the effects of jaw stretching for people who had undergone chemo-radiotherapy in addition to standard swallow exercises showed no differences were identified in swallow competence. Similarly, a tongue strengthening exercise regimen tested by Lazarus et al. (2014) did not identify differences in outcomes between the case (n=12) and control (n=11) group. Whilst small study sizes may have been responsible for Type II errors in analysis, the lack of specificity regarding report of timing, volume and frequency of the interventions are weaknesses of many of the studies, along with inadequate numbers required for comparative trials.

It is useful to note that only two clinical trials (Zhen et al. 2012; Lazarus et al. 2014) used patient report of outcomes to determine effects of the intervention, and none of the studies reported on patient or user involvement in the design of the studies. Where quality of life and self-reported measures of swallow were used, interesting findings were identified such as the Lazarus et al. (2014) study, which demonstrated poor adherence to swallow exercises, and a trend for the intensive tongue-strengthening regimen to cause some social disruption to participants, compromising quality of life. Adherence was called compliance in the study and was measured by a weekly compliance phone call from a researcher. This method is not considered reliable as the self-report could not be verified by the research team. Unfortunately there was little discussion or exploration of why people may not adhere to exercise interventions. Similarly there was no discussion around the extent to which people's priorities were considered in the planning of the swallow therapy treatments, or

whether the lack of adherence may have been related to engagement or perceived value of the intervention.

The review identifies an important issue related to the historic lack of patient and user involvement in studies of swallow function, which limits the opportunity for people with swallow problems to influence what and why particular parameters are used in studies of swallow outcome. Whilst a randomised controlled trial may be considered gold standard to determine cause and effects, these findings may have limited value if they fail to measure what is important to the population they purport to serve, and instead measure that which is easiest or most convenient to measure. The literature review demonstrates that person specific, experiential facets of an intervention including the aims and objectives of the participant, and their adherence to recommendations, is poorly understood and infrequently explored.

Clinical trials

Four case study designs (all level four evidence) were identified in the literature review. Similar to the clinical trials, these studies explored the effects of behavioural therapy interventions on swallow competence, such as dietary modifications, advice on swallowing techniques, manoeuvres to achieve safe swallow (Nguyen et al. 2007) and the effects of maintaining oral intake throughout chemo or radiotherapy treatment whilst using preventative swallow exercises (Hutcheson et al. 2013). The effect of a chin down posture, and a supraglottic swallow technique following oral surgery (Zuydam et al. 2000), and the effect of intensive daily exercise therapy to target the muscles of swallow (Carnaby-Mann & Crary 2010) were also considered.

Swallow competence was measured in various ways, either by the degree of aspiration demonstrated on objective assessment such as video fluoroscopy (Zuydam et al. 2000; Nguyen et al. 2007; Carnaby-Mann & Crary 2010), length of gastrostomy dependence, adherence to swallow exercises, and type of diet taken via mouth (Carnaby-Mann & Crary 2010; Hutcheson et al. 2013). The Nguyen et al. (2007) group demonstrated that dietary modifications, advice on swallowing techniques and manoeuvres to optimise swallow could improve dysphagia severity in 32% of the participants, however it is not possible to know whether improvement was spontaneous as there was no control group (due to the ethical implications of withholding swallow therapy from particular patients). Similar issues with a lack of control were noted in the Zuydam et al. (2000) study, where participants in the case and control group received direct swallow therapy, so it was difficult to identify which components of therapy were effective in improving aspiration. The sample size was small (n=13) and generalisability of the results compromised. The Carnaby-Mann and Crary (2010) study explored the impact of an intensive swallow rehabilitation approach called 'McNeill swallow

therapy' (n=24) and demonstrated that people in the exercise programme were significantly more likely to show improvement in their swallow function at a post treatment re-evaluation ($p=.009$).

The case study and case control design studies explored various different components of swallow compromise following surgical and non-surgical treatment of head and neck cancer and measured the success of interventions in many different ways. Similarly to the findings of the systematic reviews, it is not possible to determine an optimal treatment intervention from these results, neither is it possible to determine what facets of these interventions the individual found beneficial, as this was not collected or reported.

Qualitative literature

The experience of dysphagia or dysphagia therapy following head and neck cancer treatment.

Seven qualitative investigations were identified in the literature review (see table 3a). Only one study explored people's experiences of dysphagia related services following head and neck cancer treatment (Nund et al. 2014d) . The remaining six studies explored either the competence of the SLT to provide psychosocial care to people with head and neck cancer (Ullrich et al. 2010), or the experiences of people following radiotherapy treatment of head and neck cancer and its impact on eating and swallowing (Larsson et al. 2003; Larsson et al. 2007; McQuestion et al. 2011; Ottosson et al. 2013; Nund et al. 2014b).

Table 3a Qualitative literature

Reference	Country	Study design/methods	Population	Findings
Larsson et al. 2003	Sweden	Qualitative interpretive phenomenology. 1:1 semi structured interviews.	N=8 Participants had received radiotherapy treatment for head and neck cancer.	Eating problems after radiotherapy are complex and exist within the context of an individual's life. Themes included 'the way of life is disturbed' people coped by 'trying to see the end, To survive'. Nursing interventions need to be individualised, and provided throughout radiotherapy treatment.
Larsson et al. 2007	Sweden	Qualitative, interpretive phenomenology	N=9 Participants had received radiotherapy treatment for head and neck cancer.	Radiotherapy treatment may disrupt daily life due to the impact of eating and drinking problems. Themes included 'Needing a hand to hold' and 'Disruption of daily life', 'Waiting in suspense' and 'Left to one's own devices'.
McQuestion et al. 2011	Canada	Qualitative, descriptive analysis. In depth 1:1 semi structured interviews.	N=17 Participants had received radiotherapy treatment for head and neck cancer.	Physical, emotional and social losses can be identified as the meaning of food and eating changes after radiotherapy treatment, health care professionals need to acknowledge these problems to provide appropriate interventions.
Nund et al. 2014a	Australia	Qualitative, descriptive phenomenology . In depth 1:1 semi structured interviews.	N=24 Participants had received radiotherapy treatment for head and neck cancer.	The holistic needs of individuals need to be identified and adequately managed by the multi disciplinary team. Themes included (1) physical changes related to swallowing; (2) emotions evoked by living with dysphagia; (3) altered perceptions and changes in appreciation of food; and (4) personal and lifestyle impacts.
Nund et al. 2014b	Australia	Qualitative descriptive Phenomenology. 1:1 semi structured interview, thematic analysis, participant verification of analysis was undertaken.	N=24 Participants received radiotherapy (+/- systemic therapy) for a primary HNC between April 2007 and April 2012. All participants had self-reported swallowing difficulties during and/or following their	People require ongoing access to dysphagia services beyond the end of radiotherapy treatment. Themes included (1) entering the unknown: life after treatment for HNC; (2) making practical adjustments to live with dysphagia; (3) making emotional adjustments to live with dysphagia; (4) accessing support outside the hospital services; and (5) perceptions

			treatment.	of dysphagia-related services.
Ottosson et al. 2013	Sweden	Qualitative, descriptive analysis. In depth 1:1 semi structured interviews.	N=13 Participants had received radiotherapy treatment for head and neck cancer.	Recovery following radiotherapy takes time, and requires targeted support from health care professionals. Themes included: 'A long journey - taking small steps to an uncertain future', 'A new way of eating', 'Eating without satisfaction', 'Challenging meals outside the family', 'Support and information - the key to a successful journey' and 'The creation and acceptance of a new normal'
Ullrich et al. 2010	Germany	Mixed methods. 1:1 semi structured interview, structured questionnaire and task based response to assess communication skills.	N=33 SLTs working with people with head and neck cancer	Speech and Language Therapists can be poorly equipped to manage complex psychological and emotional effects of head and neck cancer. Further training in psychological skills for Speech Therapists working with head and neck cancer patients is required.

The findings from the qualitative enquiries describe the complex effects of radiotherapy treatment which have physical, emotional and social consequences. Physical symptoms included needing to find and learn new ways to eat due to swallow compromise (Larsson et al. 2003; Ottosson et al. 2013), whilst managing changes in self-image as a result of treatment and unintentional weight loss (Nund et al. 2014b). Together with these physical challenges, the studies demonstrated that people experienced emotional compromise, such as fear, anxiety (Nund et al. 2014b) and despair (Larsson et al. 2003). Emotional issues were precipitated by changes in physical function following treatment and, or as a result of, the changed meaning of food which people experienced after radiotherapy. McQuestion et al. (2011) noted that food represented more than sustaining life. For many people it was a way that caregivers expressed affection, nurturing and love, and it reminded people of family gatherings or childhood. Physical and emotional symptoms experienced resulted in social disruption, such as a loss of togetherness at meal times (Larsson et al. 2003).

There were four studies which considered ways the complex bio-psychosocial (biological, psychological and social) symptoms of treatment may be managed. Ullrich et al. (2010) assessed the competency of SLTs to provide psychosocial care to people with head and neck cancer by asking 33 SLTs to self-assess their communication skills. The information gathered was triangulated with interviews with the SLT and assessment by psychotherapists to examine how individual therapists would theoretically manage challenging clinical presentations. The study acknowledged that the SLT may spend a large proportion of time discussing people's personal problems during a therapeutic session, and suggested that the SLT may not be adequately trained or equipped to manage these complex psychosocial needs (Ullrich et al. 2010). It is important to note that the intervention was not observed and no data were gathered from people with dysphagia regarding their perception of the competence of their SLT.

Nund et al. (2014b) used descriptive phenomenology to explore people's experiences of dysphagia following non-surgical treatment of head and neck cancer, and their experience of dysphagia related services (Nund et al. 2014d). The research used in-depth semi-structured interviews with twenty four participants at around 16 months following radiotherapy. The findings included physical alterations to swallow, the emotional effect of dysphagia, changed perceptions of food, and effects on personal life and lifestyle (Nund et al. 2014b). Recommendations from the research included developing services to support the multi-faceted emotional physical and social issues people face following radiotherapy treatment, such as supporting the person's family with education and training about eating and swallowing. The use of descriptive rather than interpretive phenomenological approach may have limited the potential for theory generation from the data in

this study. Also the findings are specific to the effects of non-surgical treatment for head and neck cancer. Larsson et al. (2007) published on a similar subject, following interviews with people at around eight weeks following radiotherapy uncovering themes from the data which included: 'disruption of daily life', 'waiting in suspense', 'left to one's own devices', and 'needing a hand to hold'. Larsson et al. (2007) focused on the importance of the nurse-patient relationship following radiotherapy and did not explore the role of the SLT for people with swallowing problems or the post-surgical phase.

McQuestion et al. (2011) carried out 17 interviews with people who had received radiotherapy treatment for head and neck cancer. The group developed concepts about the symbolic meaning of food and suggested implications for practice that included: acknowledging the significance of eating problems, encouraging self-management, providing therapeutic education, empowerment, and social support. McQuestion et al. (2011) also explained that better preparation is required in the post treatment phase to support people to navigate their new normal being, and that education and support from health care professionals regarding how best to manage these issues is vital. The suggestions made by McQuestion et al. (2011) are a logical progression from the qualitative analysis gathered in the study, however the data is limited by the lack of post-surgical experiences. Many of the experiences described by the participants pertain to specific symptoms of radiotherapy such as dry mouth, therefore they are inadequate for post-surgical practice development, where specific physiological process impacts on swallow in different ways. This is a limitation of all of the qualitative reports, none of which explores the post-surgical phase of treatment. No ethnographic studies were identified in the literature search. Other limitations of the studies include the lack of respondent validation of themes derived from the data. Only the Nund et al. (2014b) study verified the themes with participants.

Models of dysphagia therapy interventions

No models of dysphagia therapy interventions were identified in the qualitative or quantitative studies within the literature review. This is an important omission to note as the lack of supporting literature reflects the limited understanding about how swallow therapy interventions should be provided optimally and delivered, in order to meet the needs of the individual.

Discussion

The literature review identified research which predominantly explored the role of SLTs to rehabilitate swallow following chemotherapy or radiotherapy treatment, and to manage physical symptoms. There was very limited research exploring the post-surgical phase of treatment, or people's experiences of therapy. This may be due to the challenge of exploring such a complex and

heterogeneous group of people, who undergo numerous types and approaches of reconstructions of the oral cavity. It is also possible that the researchers' own bias towards enquiry of what is traditionally valued, and alignment with the medical model influenced the predominance of quantitative investigations.

From this review it is not possible to determine whether any particular impairment based rehabilitation intervention is most effective for people with dysphagia. Each study used different interventions, on different populations, with different outcome measures, so it is not possible to compare the effects of these treatments, nor identify for which populations specific interventions are more effective. Furthermore, the majority of dysphagia therapy research focussed on the exploration and assessment of impairment based aspects of interventions. This was an interesting finding as the qualitative research available suggested that people require interventions which meet their changing and complex holistic needs following head and neck cancer treatments, thus the SLT may spend periods of time talking to people and supporting them with the psychosocial issues with which they present (Ullrich et al. 2010). Despite this, no studies explored how an SLT may provide swallow therapy interventions to impact on the things people explained were important to them, such as the changed meaning of food or coping with changes to social life and altered body image. Rather, authors presented concepts about what elements of care may need to be included in interventions (McQuestion et al. 2011; Nund et al. 2014c), which had not been assimilated into any of the case series, case study or randomised controlled designs.

No theory or therapeutic models were identified in the literature review, unlike theory development in the nursing profession (Chinn & Kramer 1999) where a comprehensive review of the chronology of conceptual models in nursing from 1952-1989 is evident. There is no example of theory development or theory application in the field of speech and language therapy interventions for people with swallowing problems, and there was a notable lack of patient and user involvement throughout this literature review. Current swallow therapy interventions are generated on the basis of biological symptoms, with limited theoretical rationale based on the needs of the whole person. It is therefore pertinent that Ullrich (2010) questioned how the SLT can provide effective psychological care alongside physical rehabilitation for swallow compromise, issues which were not raised in the clinical trials included in this review and remain unanswered in the wider available literature.

This systematic literature review raises some important questions. As there are no examples of theory application or development to guide swallow therapy interventions, do pertinent theories about rehabilitation exist outside of the specialism which could inform swallow therapy interventions? If so, are they sufficient or do they require development? Are there examples of how

people experience therapeutic interventions in wider literature which may inform the development of swallow therapy intervention? Could theories on health behaviour change be adapted to develop this specific area of clinical practice? In order to answer these questions a further explorative review was undertaken, to consider the complexities discussed in this systematic review and to identify important data which may have been omitted due to the deliberately specific search terms.

Chapter 2 Exploration of theories and philosophies

Introduction

This chapter explores theories and philosophies which have the potential to develop therapeutic interventions for people who undergo swallow therapy following head and neck cancer surgery. This exploration was undertaken to develop the information gathered in the systematic review of the previous chapter, and to consider questions which the review raised. The review generated several questions, including whether literature explored how a person may experience a therapeutic intervention beyond swallow therapy alone, whether theories or models of care existed outside of the speech and language specialism and could be effectively applied to swallow therapy, and whether models of behaviour therapy could be applied to this specialism. This subsequent exploration was carried out to consider information from different theoretical perspectives, and to consider literature from a wider evidence base which had been excluded from the systematic review due to the methodological approach and focus on only the post-surgical phase after head and neck cancer surgery.

Method

To gather a broad perspective on the issues raised within the systematic review a less structured approach to data searching was conducted. Hand searching text books, seminal texts, reference lists from the systematic review and information from experts informed this review.

The first section of the narrative review explores rehabilitation concepts and theories utilised outside of the head and neck cancer and speech therapy specialisms. These concepts and philosophies were identified in the first instance following guidance from experts in the field at the upgrade viva for this doctoral work. They emerged from diverse sociological and clinical areas outside the head and neck cancer specialism and were considered to have potential clinical application as they could address some of the questions posed in the literature review. Further reading was undertaken to explore how they may influence interventions for people with head and neck cancer. The International Classification of Functioning , Disability and Health (WHO 2001) was considered an important contribution to rehabilitation science, as it considers function in terms of the health condition, the environment and individual factors. The Transitions and Life Threads Model applied to stroke rehabilitation by Ellis-Hill et al. (2008) is also discussed alongside goal orientated therapy (Gingerich & Eisengart 2000). These theories have been previously considered for use in a rehabilitation environment. The Capabilities Approach is a theory developed by the economist Amartya Sen (2008) which is described along with the potential application for its use in a head and

neck cancer context, as it explores the individual and their concepts about what a good and meaningful life may be.

The second section of this narrative review explores literature about how a person may experience diagnosis and therapeutic treatment of cancer and disease, and head and neck cancer. Work by Frank (1995), Little et al. (1998), Kalanithi (2016) and Carel (2008) inform the questions raised in the previous review, about whether information exists outside of the speech and language therapy specialism which could provide insight into how people experience health related interventions.

The third section of the review considers well established theories on health behaviour, and whether their principles may be applied to developing swallow therapy interventions. The Behaviour Change Model by Prochaska and DiClemente (1984), the Theory of Planned Behaviour (Ajzen 1991) and the Health Belief model (Janz & Becker 1984) are all explored and are followed by a discussion and conclusion. These theories were identified as they were widely referenced in the literature and were reported to have valuable potential influence on rehabilitation interventions (Nieuwenhuijsen et al. 2006).

Rehabilitation concepts and theories

The International Classification of Functioning , Disability and Health (WHO 2001)

The international classification of Functioning, disability and health is a framework developed by the World Health Organisation. It uses specific language and definitions to describe disability in terms of the physical condition, but also the impact of the condition on participation and social interaction. The model uses standardised scoring to provide information on health status rather than simply the nature of the disease process, so large data sets can be collected about various different diseases and the effect on the individual's life.

The International Classification of Functioning, Disability and Health (ICF) is an important contribution to rehabilitation science as it provides an opportunity to recognise the impact of disability on the individual and their life, moving beyond the biology of disease. The terminology and process of measurement also means that it is possible to compare the impact of different diseases on specific groups of individuals and to consider the relationships that may exist between health status and function.

The model can be used as a data collection tool, to set goals, measure treatment outcomes and to identify the requirement for specific interventions. Tschiesner et al. (2010) developed core head and neck cancer sub sets within the ICF, to differentiate between specific anatomical locations and the impact on body functions, activities, participation and environmental factors. This improved the

tools specificity for use with this patient population. Nund et al. (2014a) also identified correlations between themes from qualitative interviews with people who had non-surgical treatment for head and neck cancer and the ICF framework. Nund et al. (2014a) successfully mapped 69 categories from their interviews to 52 of the ICF codes.

Tschiesner et al. (2010) and Nund et al. (2014a) have demonstrated the application of the ICF both to identify the nature of physical compromise following head and neck cancer treatment and to describe the impact on the individual and their life. Whilst it is clear that this framework has great value in describing the nature of disease and its implications, it is less clear how this structured framework may be of practical use in a clinical setting to meet the complex and multifaceted needs of the individual. To recognise that an individual reports challenges within ICF code d760 (Family relationships), is of great importance, however understanding what this disruption means to the individual and how the clinician may begin to provide support and rehabilitation to improve this situation is a very different issue. The answers to these questions are likely to be key components of improving clinical outcomes. It is not yet clear how this may be achieved in the post-surgical phase of head and neck cancer treatment.

Life threads mode - Ellis Hill (Ellis-Hill et al. 2008)

The life threads model was created by Ellis-Hill based on concepts of psychological and sociological literature, with specific focus on narrative theory (Ellis-Hill et al. 2008). The model explores how the life stories that a person tells and describes themselves or their social situation by can form a past, present and future self-representation. Threads may represent relationships; where two people work closely together the threads are intertwined. When the relationship changes and distance between individuals exists, the threads may loosen, or run parallel with one another. The authors explain that identity and sense of self are not static; they are fluid and influenced by meta-narrative, where other people and social environments affect and inform these life threads (Ellis-Hill et al. 2008). The model also proposes that the story a person tells can form stability and coherence in an individual's life, linking the past and that which has been, to the unknown future. The concept that the past and experiences may help map a person's future is central to the model, as is the idea that there is an alteration to the ways people make decisions and conceptualise themselves following diagnosis of a long term condition.

Ellis-Hill et al. (2008) explain that rehabilitation processes are not simply about physical recovery, rather that they re-establish social, psychological processes and life threads. This concept is a strength of the model, as rehabilitation outcomes are more traditionally measured by tools which demonstrate physical recovery alone, as demonstrated in the previous systematic review.

Therefore, the life threads model may have value and application in head and neck cancer rehabilitation, where despite recognition that people experience physical and psychosocial symptoms as a result of diagnosis and treatment there is little exploration of how these may be identified or improved by health care professionals. The Model encourages people to avoid focus on loss of the former self, and to look forward by incorporating concepts about “being with” people therapeutically, not simply doing things during rehabilitation to regain physical function. This acknowledgement of the self, and the multi-dimensional healing which goes on in rehabilitation but is seldom discussed, is of particular relevance to this research study, which aims to explore what components of care people value, and why.

Goal orientated therapy

Goal orientated therapy has been explored in many areas of health interventions. The format of the goal setting varies, and may be identified in interventions such as ‘Solution Focused brief Therapy’ or ‘Coaching’. Wade (1998) explains that goal setting refers to identifying and agreeing goals between a patient and therapist or other interested party. A postal survey of rehabilitation specialists in the UK, carried out by Holliday et al. (2005), demonstrated that many rehabilitation teams use goal orientated therapy, although the nature of the goal identification varies. Some multi-disciplinary teams identified patient goals without the patient being present. Parry (2004) suggests that the variability in goal setting practice may be due to the time and skill required by the therapist to establish these goals. It is also possible that tasks rather than goals influence therapeutic interventions, due to historical practice and institutional ‘norms’ within a hospital or care setting.

Elements of coaching may be incorporated into dysphagia therapy interventions, such as helping people identify issues or concerns, supporting people to define goals and providing structured support programmes. Similarly, principles of Solution Focused Brief Therapy may be utilised to help establish the aims and objectives of therapy. Solution Focused Brief Therapy uses specific questioning and therapeutic discussion to orientate a person to a life without their presenting complaint. The therapy encourages a person to consider how life would feel without the problem, and to identify solutions to the issues they experience, rather than focusing on the problem its self (Gingerich & Eisengart 2000), similar to the concepts identified in the life threads model. Both coaching and Solution Focused Brief Therapy may be delivered in a manualised structured format, with specific techniques and approaches provided by a therapist who has been trained in either discipline.

It is unclear whether goal setting or coaching would be appropriate for use in the acute post-surgical setting after head and neck cancer surgery when people can be acutely unwell. It is unclear whether

people are able to generate their own aims and objectives post-surgery and self-manage components of their physical and emotional compromise, or whether the severity and complexity of the problem requires deliberate direction from a therapist.

Capabilities approach - Amartya Sen (Sen 2008)

The Capabilities approach is an economic theory which provides and explores a framework to consider the components of a good life. It is not traditionally used in studies exploring rehabilitation, but was included in this review following an article by Burchardt (2004) which discussed the social model of disability, and the potential application of the Capabilities approach. A person's resources, function (being and doing), capabilities (tasks which a person can complete) and the overall utility of these elements are all considered important to achieve a meaningful life. The Capabilities approach describes a person's ability to do valuable acts or 'reach valuable states of being' (Sen 2008) and seeks to identify objects of value, and their relative values. A simple example may be in the case of a person with head and neck cancer where the object of value is achieving adequate nutrition and hydration. A person's capability to achieve this relies on their social support, access to food and ability to swallow. The relative value of achieving adequate nutrition may be realised through a variety of components not simply a person's function, but their ability to engage, and their freedoms to make choices. Sen (2008) explains that the Capabilities approach involves Aristotelian concepts of the human good which considers the function of man and then life in the sense of activity (Sen 2008).

It seems that a positivist, function focused evaluation of the impact of diagnosis and treatment of head and neck cancer may omit important philosophical concepts about being human and the sense of activity which Sen (2008) identifies. This work (2008) provides insight into the risk of measuring what people with cancer can or can't do, rather than providing opportunities to explore a person's full and potentially complex issues, in order to achieve their own meaningful clinical outcomes.

The experience of diagnosis and treatment

Experiential literature.

Arthur Frank (1995) and Havi Carel (2008) both describe the value of phenomenology to uncover and consider complex components of health and the experience of disease. Carel (2008) describes her experiences as a researcher and a person with life limiting illness in her book, 'Illness; the art of living'. Carel's work shares concepts raised in the Capabilities approach (Sen 2008) specifically that dysfunction is inherently related to well-being and that a person's world and freedoms shrink when they have an illness impacting on their social function.

Carel (2008) considers philosophy as a central issue regarding the understanding of illness and the development of health care interventions. Carel (2008) explains that, with influence from the philosophers Epicurus and Heidegger in particular, there is potential to combine the first person description of being, with the third person perspective or external reflection on what an experience may be. She suggests that rather than using resources to observe and plot decline (as in chronic illness there may not be any real control or change in disease or function) instead, time should be spent crafting and attributing value to one's inner state of being. The work of Sen (2008) and Carel (2008) identify complexities and disconnects between what a body is objectively capable of, what wellbeing may look like to the observer, and a person's perception of wellbeing. An ontological paradigm has the potential to explore what these differing perspectives may be, how they relate to one another, and how their value may be captured. However the positivist paradigm which influences much healthcare research may preclude the emergence of these complex influential relationships.

In 2016 Kalanithi (2016) wrote 'When breath becomes air', about his experience of diagnosis and treatment of lung cancer. He described the "featureless wasteland of my own mortality and finding no traction in the realms of scientific studies" (page 148). The lens which Kalanithi (2016) creates through his use of language and deliberate recording of his experience provides a unique insight into what his experience felt like. His perspective enables healthcare professionals to consider the position and experience of a patient with personal clarity, rather than with preconceived or medicalised ideas about what disease may feel like. The book documents Kalanithi's transition from being a fit and well neurosurgeon, through to his palliation and death. After his death, Kalanithi's wife documented her perspective in the epilogue. Lucy Kalanithi explained that her husband had done more than "just describe the terrain. He traversed it bravely" (page 215). This quote captures the essence of the interface between being and doing, as described by Sen (2008) and Carel (2008), and raises the question again about why the perspective of the individual is seldom used in health research when it offers such potential insight and value.

When individual narratives are exposed in this way, complex components of experience may become obvious; for example the theme of transition in Kalanithi's account (Kalanithi 2016). This transition may be considered a kind of liminality. Liminality is the transition or indeterminate phase between two states. This concept was first explored by the anthropologist Gennep (1908), and latterly Turner (1987). Early concepts of liminality were concerned with social and cultural transitions, and being on a threshold, such as birth, marriage and death. Rites of passage are related to these transitions where an individual severs social and cultural relationships, enters into a

transient 'in-between phase' and then takes up a new social and cultural position (Scott 2014). Kalanithi transitioned from a position of employment as a doctor with autonomy and choice about his career and personal life. His 'in-between' phase seemed to be when he received treatment and became a patient who still interfaced with other doctors such as his oncologist but without the autonomy and choice making he had previously. He was then cared for by his wife and family, when he had provided the caring before his illness, and finally his breath became air.

Liminality has been identified in the experience of a cancer diagnosis and its treatment (Little et al. 1998). Little et al. (1998) explain that as the body is the place that both the self and disease exist, when fundamental changes such as surgery happen, not only the disease, but the self may also be altered. Little et al. (1998) offer a specific interpretation of liminality. Firstly, the process is not easy to identify or define specific to one moment alone. Secondly, liminality is not static, but may continue for an indeterminate length of time. Little et al. (1998) suggest that there may be an acute and chronic liminal phase at diagnosis and then beyond. The concept of liminality has not yet been identified in people who have undergone surgical treatment of head and neck cancer, however it can be recognised in Kalanithi's (2016) work, when he describes his diagnosis, treatment and palliative phase of his disease. It seems possible that many people may experience this type of transition and the 'in-between' phase following diagnosis and treatment of cancer, which has the potential to change not just one's physical being but also sense of self.

The power of the individual's voice to uncover subtle and complex realities is a theme which runs through the work of Carel (2008) and Frank (1995). Arthur Frank's (1995) 'Wounded story teller' describes how illness can cause people to become citizens of 'that other place', where 'well' people don't reside. He explores concepts about how people's metaphorical voices can become lost and require reclaiming. Frank (1995) suggests that narratives can help guide medical interventions using personal lived experience as the premise, allowing the person who has undergone the illness to be an expert witness, to shape the nature of the interventions they receive (Frank 1995). The value of narrative was written about by Frank over twenty years ago, and yet is still infrequently employed in rehabilitation interventions.

Work by Frank (1995), Carel (2008) Kalanithi (2016) and Little et al. (1998) identify valuable experiential components of diagnosis and treatment of life limiting illnesses, by exploring the perspective of the person with the disease. By listening to the voice of the person, the authors suggest the processes that people experience may become obvious, their transitions through time may be better understood, and the potential for providing meaningful and specific interventions

may be achieved. It is unclear why this practice is not currently embedded within clinical interventions or why it is not readily adopted by clinicians.

It is possible that healthcare professionals limit the use of narrative in healthcare interventions due to the perceived amount of time it would take to listen to patients and allow them to explain and describe their stories and experiences. It is also possible that the potential for vulnerability and unbounded emotion, uncovered by a patient telling their story, may be challenging for a healthcare professional to observe and be part of, and therefore perhaps these opportunities are deliberately avoided. To be exposed to painful, sad and traumatic experience frequently would be challenging, and it may be that if a healthcare professional feels ill equipped to manage this kind of situation for themselves or the patient, they deliberately or unconsciously avoid it. Equally, a person may not feel comfortable disclosing, unloading, or discussing this private information with a health care professional.

Healthcare interventions generally focus on making things and people better, so listening to a person and providing them with space may not be seen to match this approach. This type of intervention may not make someone better in binary terms, like providing pain relief might. However, this does not render the intervention pointless or useless. To ensure a patient has been heard, and has had value attributed to their feelings and admission of emotion is likely to be an important intervention even though it is less tangible than giving pain relief for example. It is possible that simply being with a person and acknowledging their hardship could itself be of great value. Research of this kind, which explores the perception of the person receiving care, could help provide the permission clinicians may require to engage with this type of intervention. It is possible that this truly person centred approach may in fact reduce time spent on other interventions that people may neither want or need.

Behaviour change models

Health behaviour models explore the ways in which people respond to illness, and manage change as a result of illness or disease, and engage with interventions. Three well known models are explored in this section to help understand how therapeutic interventions for people with head and neck cancer may have effect, and indeed whether experiential components of care could be embedded within therapy.

The Behaviour Change or Transtheoretical model of behaviour change was developed by Prochaska and DiClemente in the 1980's (Prochaska & DiClemente 1983; Prochaska & DiClemente 1984). The model is based on the proposition that change happens over time, and a sequence of specific stages may be identified within any health behaviour change. These stages include pre-contemplation,

contemplation, preparation, action, maintenance and termination (Prochaska 2003). The model is based on information gathered from people who gave up smoking with, and without, formalised support in the 1980s (Prochaska & Diclemente 1983). This research identified that in order for smoking cessation to be most effective, interventions should be tailored to reflect people's stage of change.

The behaviour change model suggests that change happens on a continuum, and therefore binary measures such as pass or fail are not applicable to measure the success of an intervention. Furthermore, Prochaska (2003) explains that an 'action paradigm' is an inappropriate context in which to be providing health behaviour interventions. The 'action paradigm' refers to the way in which an action or behaviour is deemed effective or not. Instead, the degree to which a person has moved through the stages of change should inform, and help target interventions. Prochaska (2003) suggests that our 'action' driven society and culture only recognises behaviour change in terms of achieving the 'desired action' not the process of change. The action paradigm, and pass fail measures are used frequently in swallow therapy interventions, with tools used to identify success, which Prochaska (2003) suggests may not be appropriate for use especially in the case of complex and staged health behaviour. Carel (2008) also suggests that this approach of plotting decline may not be suitable or helpful for people with chronic issues yet this practice is widespread in healthcare.

The Behaviour Change Model does not attempt to explore the relationship between psychological, psychosocial and physical processes as described in earlier sections of this literature review, nor how these phenomena may impact on change. Instead, the model focuses on the process of change itself, and provides rationale for transition between specific positions on the change continuum. The change processes include concepts such as 'social liberation' (opportunities in a person's environment which present new alternatives) and 'self-liberation' (similar to will power). Prochaska and DiClemente (1982) suggest that if people have more than one choice regarding behaviour change then the sense of self liberation or willpower will be enhanced, as a result of changing through choice. It is unclear whether these processes are easily applied to people with head and neck cancer post-surgery, who may experience complex emotions such as grief, anxiety, fear and loss (Parker et al. 2014). Jensen et al. (2000) discussed similar concerns with the application of the Model to manage chronic pain; since chronic pain is influenced by a large number of behaviours and attitudes, the Model may not be specific enough for use. Wilson and Schlam (2004) explain that issues with application of the model relate to limitations with the empirical data used in the development phase, which was solely focussed on smoking cessation.

It is likely that components of the behaviour change model have potential application to dysphagia therapy interventions; such as the concept of change existing on a continuum, and the rejection of an 'action paradigm'. However, the complexity of a therapeutic intervention provided to people with both physical and emotional issues following head and neck cancer surgery means that a single theory of this kind, developed without empirical data from appropriate participants, is unlikely to help determine the impact of a therapeutic intervention or help map the needs of people post-surgery.

Theory of planned behaviour (Ajzen 1991)

The theory of planned behaviour suggests that behaviours are informed and determined by intentions and perceived control (Ajzen 1991). Ajzen (1991) identifies three types of belief; behavioural, normative and control and suggests that an understanding of these beliefs and their underlying processes help predict behaviours, and therefore plan interventions. Behavioural beliefs are individual, and may moderate a person's attitude towards a specific behaviour or outcome; they may also be shaped by a person's previous experiences. Normative beliefs are the influence of social context on an individual's behaviour, for example peer values and expectations. Control beliefs refer to a person's belief that they can achieve a task or behaviour. Control beliefs are influenced by both normative and behavioural factors (Boslaugh 2013). This theory has been widely used to inform a variety of interventions including weight loss (Schifter & Ajzen 1985) and alcohol abuse prevention (Marcoux & Shope 1997).

It is possible that elements of this theory could explain why and when particular swallow therapy interventions may have effect as the theory has been successfully applied to many diverse social and health science disciplines (Armitage & Conner 2001). A particular strength of the theory is the inclusion and recognition of individual and group influences on behaviour (normative beliefs). As noted in previous chapters, swallowing problems may impact on a person's sense of self, social experiences and quality of life (Nguyen et al. 2005), therefore application of this theory could help predict and support people to manage the effects of dysphagia, by exploring and including social networks and support in therapy sessions.

Andrykowski et al. (2006) found that the theory of planned behaviour could help predict behavioural intentions of people who had been diagnosed with cancer. The study (Andrykowski et al. 2006) discussed the 'positive' behavioural changes people may make after a cancer diagnosis, and 'benefit-finding', where people seek to make positive changes to their lifestyles. Positive behavioural changes and benefit finding have not yet been identified in literature about head and neck cancer, rather, there is recognised fluctuation in the effects of the disease, from the psychological impact of

diagnosis, to the physical effects of gruelling treatment interventions, and living with altered function (Wissinger et al. 2014). This variability may challenge the application of a model which predicts health behaviours based on peoples sense of control or beliefs, as these are unlikely to be static or linear for people with head and neck cancer. As described, the identification of behavioural, normative and control beliefs may be useful concepts for Speech and Language Therapists to help determine barriers or facilitators of therapy. It is unlikely, however, that these concepts alone would be a sufficient theoretical basis to provide a swallow therapy intervention as they fail to account for the impact of external factors, such as the effects of treatment and health status on a person's engagement.

Health belief model (Janz & Becker 1984)

The Health Belief Model (Janz & Becker 1984) was originally developed to explore why people engage or don't engage with health screening opportunities, but it has subsequently been applied in differing contexts. The model is based on two propositions about what influences engagement with health behaviours. The first proposition is that an individual's perception of the importance of a goal will influence their engagement, the second proposition is that a person's perception of the probability they can achieve the goal is a dominant factor in their engagement.

Janz and Becker (1984) explain four further concepts which underpin the model. These are perceived susceptibility (a person's belief about the likelihood they may get the disease), perceived severity (if they get the disease how severe it may be, this includes medical and social consequences), perceived benefits (whether someone will engage with behaviour to avoid the disease) and perceived barriers (the impact or cost of interventions such as injury or possible side effects). Comparisons may be drawn between elements of the health belief model and the behavioural belief facet of the Theory of Planned Behaviour, where a person's belief influences behavioural changes. However, in a study by Zimmerman and Vernberg (1994) a meta-analysis identified that the health belief model was less powerful at predicting outcome variables in health behaviour changes when compared with the Theory of Planned Behaviour.

The Health Belief Model was developed from concepts about how people engage with and value goals, specifically related to health beliefs. The model does not explore the impact of a person's social context, or the effect that pre-existing disease may have on health behaviours. For example, if a person has been diagnosed with head and neck cancer their ability to engage with complex swallow therapy may be compromised by their health and wellbeing, rather than simply their beliefs about the intervention. Furthermore, the model does not explore the possibility that people may have multiple goals, such as survival, maintaining independence, and weight management. There is

no discussion around how these competing goals may be managed, or how they impact on one another. The model does identify important issues around health beliefs, and how these may impact on a person's value of a goal. The application of this information may help Speech and Language Therapists to target therapeutic interventions, however the model would require adaptation to be used in a swallow therapy context.

Discussion

This review presents approaches and theories from a range of specialities dealing with change and long term conditions, which have the potential to contribute to the care of people with head and neck cancer. The review has also considered what may influence how people deal and cope with their experiences. Whilst it is possible, and useful, for researchers to stratify experiences into psychological, physical and psychosocial categories, it is important to recognise that these experiences do not happen in isolation, as illustrated by the experiential data described. With this understanding in mind, it is unsurprising that there is not a single gold standard therapeutic intervention or best practice guideline for SLTs working with people with head and neck cancer. It seems unrealistic that a single intervention alone, be it physical or psychosocial in nature, would meet the needs of this complex group of people. Instead, exploring which principles and approaches help create and underpin an optimal intervention from the perspective of the individual may be more appropriate.

This review uncovers the experiential elements of a cancer diagnosis, theory on the value of narratives to shape interventions, and models which could support the provision of an intervention. However there is not yet a clear way to determine what an optimal swallow therapy intervention would look like and how it could be delivered to meet the needs of the individual within the NHS. Some experiences of people with head and neck cancer have been identified, along with the potential benefits of a therapeutic intervention, but the bridge between this theory and the practicalities of providing an intervention has not yet been established.

The review identified useful insights into health behaviours, experiences and theories which may underpin behaviours. The following components were deemed of value by the researcher as a result of their potential clinical application:

- Change is staged and happens on a continuum (Prochaska, 2003)
- Binary measures of outcome may be insufficient (Prochaska, 2003)
- The emotional, cognitive and behavioural elements of response to disease and function are likely to impact on one another (Jensen et al., 2000)

- A model needs to be context specific, developed using appropriate empirical data (Wilson and Schlam, 2004)
- Behaviour is influenced by personal beliefs, the social context and personal experiences (Ajzen, 1991)
- A person's perception of the importance of a goal, and the likelihood they will achieve it, influences their engagement (Janz and Becker, 1984)
- When a person has cancer their voice may be lost and their sense of self altered (Frank 1995)
- A person may experience a transition, or liminal state following diagnosis of cancer which may go on for an indeterminate amount of time (Little et al. 1998)
- Time and energy may be spent effectively ,crafting and attributing value to one's inner state of being, rather than simply plotting physical decline (Carel 2008)
- Identifying objects of value, and their relative value to the individual, is important when attempting to understand the components of a meaningful life and well-being (Sen 2008)

Any dysphagia intervention is likely to be more than the sum of its parts, and the success of the transaction between the therapist and the person with dysphagia is itself a detailed and complex phenomenon not yet fully explored within the context of head and neck cancer. As there is no information around how people have experienced post-surgical dysphagia therapy, or indeed how they would like it to be provided, there is a requirement to explore this issue. The data collection and analysis helps identify how existing theory, models and information on people's experiences of head and neck cancer may be triangulated to ensure comprehensive and holistic interventions are provided.

Chapter 3 Methodology

The following chapter describes the methodological approach used to explore the experiences of people who underwent swallow therapy following head and neck cancer surgery. This research study was conducted to explore the experience of swallow therapy in order to inform the development of a swallow therapy intervention model for SLTs working with this group of people. The research focused solely on the immediate post-surgical phase, as swallow compromise is at its peak following surgery due to altered anatomy, sensation changes in the oral cavity, intra oral post-operative swelling and fatigue, and it is likely that this is the phase where the SLT is most likely to be able to have significant impact. Currently no research has explored interventions in this immediate post-surgical phase. The aims and objectives of the research are outlined along with the research design.

Aim

- To understand the experiences of people who receive dysphagia therapy from an SLT following surgical treatment of head and neck cancer

Objectives

- To explore the experience of people undergoing surgery for treatment of head and neck cancer.
- To explore the experience of people with swallowing difficulties following surgical treatment of head and neck cancer.
- To explore how well prepared people are for the effects of surgery on their swallow competence.
- To explore the experience of receiving dysphagia therapy from a speech and language therapist.
- To understand the components of effective or non-effective therapy from a patient's perspective.
- To inform the development of optimal swallow therapy interventions.
- To develop a therapeutic intervention model for people who have dysphagia following surgical treatment of head and neck cancer.

Phenomenology

A phenomenological methodology was chosen for this research study because the meaning of the experience of the participant and the context in which the participant receives the therapy are central to the research question (Punch 2005). Interpretive phenomenology offers the researcher the opportunity to generate theory based on people's experiences, ensuring the participant is central to the enquiry.

Phenomenology aims to expose themes and data embedded in relationships and experiences which may not be apparent to the participant (Porter 2000). This method was originally developed by Husserl (1859-1938) who describes concepts about perceptions and memories which inform a person's view of an event or experience. Husserl believed that preconceived ideas could be bracketed in order that the individual's 'knowing' of the world they experienced could be captured and described without influence from interpretation (Reiners 2012). Bracketing refers to suspending the prior knowledge of the researcher which might otherwise influence the data. This approach may be used in descriptive phenomenological studies (Tufford & Newman 2012).

Interpretive phenomenology was developed by Heidegger (1889-1976) a student of Husserl, who believed knowledge and experience should be recognised as part of interpretive phenomenological enquiry (Maggs-Rapport 2000) and may be considered a strength of studies of this kind. The nature of 'being' rather than 'knowing' was developed by Heidegger, who explained that 'being' involved an individual's interpretation of their experience not bracketing or suspending prior knowledge (Reiners 2012). It is unlikely that an individual can ever truly bracket their prior knowledge or experiences. Whilst an individual may be aware of some bias and beliefs, others are intertwined with a person's essential self, influenced by subtle social and cultural experiences. This subjectivity is impossible to fully identify or suspend. In the case of this research, the researcher is an SLT. This clinical role means that the researcher has a prior knowledge and experience of working with people with head and neck cancer. It is not possible for this experience to be suspended, neither was it attempted. The experience of the researcher is considered an additional skill to support the research process and the rigorous methods assure the quality of all phases of the research.

Alternative methodologies

Alternative methodologies were considered for use in this study. Grounded theory methods were explored as it would have been valuable to derive theoretical concepts from the social interactions (Corbin & Strauss 1990) associated with eating and drinking. Grounded theory methodologies help uncover complexities that may exist within social frameworks, simultaneously collecting and analysing data. This approach may have provided insights into ways swallow problems impact on a

range of components of life and relationships, by gathering information from numerous subjects involved in the post-surgical recovery phase (Baker et al. 1992).

An ethnographic methodology was also considered so that the experience and culture that contextualised the individual's experience could be examined (Willis & Trondman 2000). However, the results of the literature reviews identified the limited information available around the experience of people who had undergone head and neck cancer surgery, despite the potential value of individual description of disease as demonstrated by Kalanithi (2016). Grounded theory and ethnographic methodologies had the potential to explore and identify discrete components of this poorly understood subject. Both approaches would have been appropriate to study the post-surgical phase of treatment. Ultimately interpretive phenomenology was chosen as it was able to meet the aims and objectives of the research question in a comprehensive way, specifically regarding the nature of the lived experience of the individual.

With this information in mind, a decision was made to pursue a phenomenological methodology so that the experience perception and understanding of the participant informed the findings in this poorly understood subject area.

Design

The study used in-depth, semi-structured, 1:1, face to face interviews with people who received swallow therapy following surgical treatment of head and neck cancer. The interviews took place whilst the participant was an inpatient in hospital after receiving swallow therapy, before they were discharged home at around day 7 to day 14 post surgery. The interviews were audio recorded and conducted by the researcher. The researcher works as an SLT in the study institution so to reduce the potential of bias, she did not provide any therapeutic interventions to eligible participants during the recruitment phase. Whilst recruiting participants from multiple treatment centres would strengthen this study, time and funding limitations precluded this possibility. Four other SLTs in the team provided swallow therapy to the participants according to standard clinical practice within the institution.

Ethics

Written consent was obtained from the participants before inclusion in the study. Full ethical approval was granted from the University of Southampton Ethics and Research Governance Online (ERGO) (reference: 12133) and the NHS Integrated Research Application System (IRAS) (IRAS reference: 164120).

All person identifiable data was anonymised. The nature and relative rarity of head and neck cancer surgery of this kind coupled with identification of the researcher and the study centre where she is employed meant that specific and detailed information about participants needed to be omitted from the analysis. This made the description and introduction to the informants (chapter four) challenging, as information about personal attributes, coping style and family dynamics may have enabled readers to more comprehensively understand individual participants. However preserving the agreement with participants to remain anonymous was a priority.

Participation in the interview had the potential to cause distress to the participants. At the outset of the study it was not possible to predict how people may feel if they were asked to relive, or review their post-surgical experience whilst still in hospital, however the clinical experience of the researcher suggested that people may feel a range of challenging emotions. With this in mind, and aiming to mitigate for the potential harm of the interview, the following safeguards were put in place.

The interview took place on the ward the participant was staying on, to enable the person to feel at ease and comfortable with the physical environment, without needing to move to an unfamiliar interview room elsewhere in the hospital. As a result of the interview taking place on the ward, the participant was in close proximity to nursing staff and to their support network such as the clinical nurse specialist and the head and neck counsellor. The individual was informed before the interview that these members of the team could attend if required. Nursing staff were aware the individuals were being interviewed, and were informed when the interview had finished so that any issues or concerns regarding the interview could be fed-back and discussed immediately with another qualified clinician if required. There was a potential that this proximity to the ward environment may have made the participants feel inhibited. With this in mind, each individual was asked whether they felt comfortable having their interview on the ward at an agreed time, and were given the opportunity to decline or discuss with the researcher at several time points.

It was also possible that the researcher may have observed or become aware of information regarding care or therapeutic interventions which required action from a clinical governance perspective. The researcher is a registered member of the Health and Care Professions Council and the Royal College of Speech and Language Therapists. These professional registrations dictate that registrants must adhere to specific standards of conduct, ethics and performance regarding incidents of compromise to an individual receiving care. With this in mind the following statement was read to the participants at the beginning of the interview, to make the position of the researcher and her responsibilities explicit:

“This interview is confidential between yourself and the research team. Individual information will not be shared with the clinical team, so you can feel confident about discussing your experiences. If you disclose any information which may be of harm to yourself or someone else, this confidentiality will be broken, so the information can be passed on to the appropriate team to support you.”

Alongside factors such as physical and emotional challenge, the timing of the interview also meant that people were potentially particularly vulnerable. Potential participants had been approached before their surgery, and the nature of the research had been explained to them. People were informed that consent to partake in the research would be taken on the inpatient ward post-operatively. Whilst this approach ensured people had adequate time to consider their inclusion in the study, it was impossible for people to predict whether they would be prepared to take part in the interview post operatively, whilst they had altered speech and potentially felt unwell. It was therefore paramount that the researcher did not in any way coerce, pressure, or make people feel obliged to take part in the research at a time when they were most vulnerable.

To ensure people consented as freely and deliberately as possible, the researcher checked with the consultant surgeon that to the best of their knowledge the surgeon felt the potential participant was physically and emotionally suitable to partake in the research on the day she planned to take consent for inclusion. Furthermore, discussion with the participant was non suggestive and made clear that the interview was entirely voluntary. Again, the professional and clinical responsibility of the researcher also influenced this process, ensuring that no person's care, wellbeing, or autonomy to make a decision not to participate was overlooked or dismissed, especially given that this group of people had compromised communicative ability.

The researcher works as a SLT within the study setting. It was possible that participants may have reported concerns or issues about their therapeutic intervention which may have placed the researcher in a challenging position regarding reporting these concerns to SLT that either were her line manager or that she line managed. From the outset it was clear that the researcher needed to define boundaries to mitigate for this potential.

As discussed, in the first instance the researcher made clear to the participant that she had a clinical responsibility to report any potential mal practice as a result of her professional registration. Concurrently, she also made clear to her clinical colleagues that the research she was undertaking was not a service evaluation. This meant that no individual feedback would be provided to the SLT team about their clinical interventions. The researcher clearly established the nature of the anonymity required from the perspective of the individual, and explained that no information from

the interview could be accessed by the clinical team. She also established that no judgement about individual therapists would be sought from the participant, rather that the components of successful or unsuccessful therapy would be discussed and considered in terms of the impact this had on their experience.

Setting

The study setting was a large teaching hospital in England. Approximately two people per week undergo surgery for treatment of head and neck cancer at the study centre (The Health and Social Care Information Centre 2012). The interview took place after the participant received swallow therapy, before they were discharged from hospital and around day 7-14 after surgery. This was done to reduce the necessity for extra visits to the hospital, as Newington and Metcalfe (2014) explain that reducing participant burden, through travel or cost involvement in research, may improve recruitment rates. The interview took place in a quiet, non-clinical room on the ward on which the participant was staying.

Sampling and sample size

Convenience sampling methods were used partly due to time and funding limitations and also because other studies in the same subject area have used a similar approach successfully (Gunn et al. 2013). Also this qualitative research does not attempt to be generalised to the whole population with head and neck cancer. It generates themes from interviews with a specific group of participants at a single centre in the UK, thus the sample does not have to represent people with head and neck cancer beyond this group. The researcher had a four month period to collect data in the study setting. Approximately two head and neck cancer reconstructions per week are conducted here. Creswell (1998) suggests 5-25 participants should be included in phenomenological research . It was predicted that if one participant was recruited per week, 16 participants could partake in the research within the limited time frame.

There are limitations of convenience sampling compared to purposive sampling. Whilst both are nonprobability sampling techniques, purposive sampling may have been more representative of the total population who have head and neck cancer. In this study 7 women and 8 men were included in the sample, their average age was 62.8 years. Recent literature reports oral cancer rates peak from age 65-69 in both men and women, in 2015 4921 men and 2434 women were diagnosed with cancer of the oral cavity, lip and pharynx in the UK (Office for National Statistics 2015), so the ratio of men to women in this study is not representative of the amount of women who are likely to undergo head and neck cancer surgery nationally.

It was anticipated that between 10-20 people would participate in the research, and recruitment would stop when either data saturation was achieved or 15 people were recruited. Unlike quantitative research, sample size may be determined at the point of data saturation, when analysis of the data ceases to identify new themes (Parahoo 1997). The data were transcribed and analysed as collected, so the point of saturation was identified in a timely manner, following the fifteenth interview.

Identification of participants

Participants were identified by the clinical nurse specialist and consultant surgeon at the weekly Multi-Disciplinary Team (MDT) meeting where all new cases of people with head and neck cancer are discussed and treatment is planned. The researcher provided a short training session on the aims and objectives of the study to the clinical nurse specialists and head and neck surgeons, and outlined eligibility criteria.

Recruitment

In an outpatient clinic appointment, before the person underwent surgery, the clinical nurse specialist explained the premise of the research study to those who were eligible, and they were given the opportunity to meet with the researcher to discuss any questions they may have had. Each eligible person was given a participant information sheet at this pre-treatment session with the clinical nurse specialist. The information sheet included the aims of the study, data collection methods and contact details for the researcher (Appendix A). The information sheet informed the individual that the researcher would approach them after their surgery whilst they were an inpatient on the head and neck ward, usually around day three post operatively. If they decided to take part in the research written consent was taken by the researcher whilst they were on the ward (Appendix B). This approach allowed the participant adequate time to consider taking part in the study.

Inclusion

- Any person undergoing reconstructive surgery and swallow therapy for treatment of head and neck cancer at the study centre.
- Reconstruction using free, pedicle, or composite flap.
- Any person over 18.
- Capacity to give consent
- English speaking

Exclusion criteria

- Primary closure for treatment of head and neck cancer i.e. no reconstruction, as this group of people rarely require swallow rehabilitation from a speech therapist.
- People with cognitive impairment.
- Total laryngectomy*.
- Reconstruction of benign disease using free or pedicle flap (including osteoradionecrosis).
- Reconstruction for primary cancer only involving the thyroid salivary glands, ear or nose.
- Unable to communicate using the English language.

*People who had undergone total laryngectomy were excluded from the study as they receive different and specific swallow and voice rehabilitation as a result of having their larynx removed.

Participant involvement

Patient and user involvement is well recognised as an important element of health research studies, and has been shown to have a positive impact on identifying research agenda, questionnaires, participant information design, and grant applications (Arain et al. 2012). A person who had swallow therapy following surgery for treatment of head and neck cancer, and expressed an interest in being involved with the research project, reviewed study procedures, helped develop the pilot and informed the interview schedule.

The pilot

A pilot of the interview schedule was conducted to test the face validity and feasibility of the questions with a person who had undergone surgical treatment of head and neck cancer and agreed to be involved in the study. Following discussion, closed questions were removed and questions were added about the participants' perception of their therapy. The pilot facilitated personal reflection on the researcher's interview style, specifically:

1. The use of fillers - using words like 'ok', 'thank you', 'hmmm', 'right' rather than 'good' 'I'm pleased' which suggested some personal involvement or judgement from the researcher. These were omitted in the final interviews with participants.
2. The importance of asking a greater number of questions about swallowing and the detail that surrounds what and how people manage.

3. The importance of “homing in” on phrases used by the participant and asking for clarification by repeating phrases used by participants, rather than focusing on completing the interview. This helped the participant reflect and consider their feelings.
4. For the researcher not to feel anxious about clarifying points to reduce the risk of inference.
5. To be confident to leave silences.
6. To stop using stock clinical phrases which could close down discussion, such as ‘that’s helpful thank you’, and instead use more open phrases such as ‘What did she do?’, ‘what did she say?’ ‘How helpful was it?’ ‘What told you that was the case?’

Feedback from the pilot also resulted in changes to the structure and wording of the interview questions, such as avoiding the use of word ‘family’ which the patient representative noted may be emotive and inappropriate for some participants.

The researcher as a data collector

The researcher is a Speech and Language Therapist in the study setting which had the potential to bias results of the data or the interpretation of the data. To reduce the potential for bias the researcher did not provide any therapy to any eligible participants, or discuss her role as a therapist with the participants in the interview. The participants were aware the researcher was an SLT within the research institution. It was possible that people would be less likely to discuss negative experiences of therapy with the researcher if she was perceived to be part of the clinical team. To reinforce her role as a researcher not a therapist, the majority of interviews took place on a Friday, which was a day the researcher did not work clinically in the study centre, and the researcher did not wear a clinical uniform. Whilst this was a subtle detail, this seemed to enable the participant to converse with the researcher aside from her clinical role, and enabled the researcher to ask questions outside of those limited to a clinical environment or context.

The clinical experience of the researcher facilitated the practical process of data collection, as the majority of participants had disordered speech, and were self-conscious about making errors or being misunderstood during the interview. The researcher was able to put the participants at ease, and interpret their speech effectively, reducing their anxieties about being interviewed which were high in the immediate post-operative phase. The data collection may have been challenging for a non-speech therapist to collect due to the difficulties in interpreting the speech, and knowing how to communicate optimally with the participants. These practical skills included using lip reading as well as auditory analysis of speech to clarify difficult to understand words, allowing the participant adequate time to clear and swallow built up oral secretions, encouraging a participant to take a drink if their mouth was so dry that speech intelligibility was poor, feeling confident to ask for word

repetitions at appropriate times without interrupting the flow of a phrase, using eye contact and silences to encourage and make the participant feel at ease and not under pressure.

The Interview

The interviews followed a semi structured format as outlined in appendix C. The questions outlined in appendix C were used as prompts and cues to structure the interview, these questions were flexible and developed in line with the discussion with the participant. In accordance with the goals of interviewing within a phenomenological paradigm, to capture the experience of the participant the interview questions were not to be leading or loaded with pre-conceived beliefs or ideas (Creswell 1998). The questions were open and designed to facilitate exploration around the experience of surgery, swallow problems, and swallow therapy.

The interviews took around one hour to complete. Participants were all able to walk independently to the quiet room on the ward, and they sat in a comfortable chair, with a glass of water and tissues within reach. Pens and paper were also available in case participants wanted to write anything down. The researcher conducted the interview after undergoing interview training at the University of Southampton. She explained that despite her role as an SLT she would not provide any therapeutic intervention to the participant. Should any unmet clinical needs be identified they would be raised with the hospital Speech and Language Therapy team if the participant was in agreement. It was possible that the participant may feel emotional during the interview or overwhelmed. In recognition of this, if the participant was in agreement, the clinical nurse specialist and dedicated counsellors would be contacted should the participant require support.

Transcription

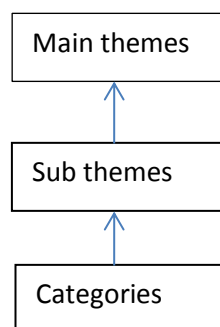
Each interview was recorded and transcribed verbatim by the researcher. Guidance on transcription was sought from published literature such as McLellan et al. (2003) who describe optimal methods of data handling, transcription and formatting. No transcription software was used as the researcher wished to immerse herself in the transcription and analysis.

Analysis

The inductive analysis phase of the data collection was guided by the approach detailed by Hycner (1985) who provides guidance on how to complete phenomenological analysis in a logical manner. Some authors recommend the use of theoretical frameworks or models to guide the analysis phases of qualitative data (Pope et al. 2000), however as there was such limited information around people's experiences of swallow therapy following surgical treatment as identified in the literature review, it was not possible to define a priori hypotheses or a predefined taxonomy to guide the

analysis phase. The use of a framework also had the potential to limit emergence of themes specific to the experience of dysphagia.

The researcher was immersed in the data as she completed the collection, transcription and coding. In the initial phase the data were transcribed, then checked for typing errors several times. The researcher then read and re-read the transcripts, whilst making notes and observations. The transcripts were then coded line by line. The interview schedule asked specific questions to meet the aims and objectives of the study. Within the answers people gave, themes began to emerge. The transcripts were printed, and each line physically was cut out, down to the smallest meaningful component. In some cases this may have been four words, for example 'I am a fighter'. In other cases this was a longer sentence or phrase. These phrases were then grouped together with other phrases, based on their meaning. When all of the transcripts underwent this process, the various groups of phrases were read and re-read. These groups became the categories, and quotes from the interviews were used as names for these categories. Categories which were similar in meaning were aligned with one another and created the sub themes. The subthemes overarched the categories, and the main themes overarched the sub themes.



The research supervisors independently agreed and thereby validated the emergent themes at various points during the data collection and analysis. The supervisors supported the analysis by checking the coding system and challenging decisions made by the researcher. This included making modifications to the analysis of the narrative, and review of the online transcripts. The supervisors also provided support to the researcher, who is a novice in the field of qualitative research, by providing regular discussion and guidance during the analysis phase. The themes were not verified by any of the participants as during the consent phase no one expressed a wish to review or partake in the research beyond the interview.

Chapter 4 Findings

This chapter gives an overview of the respondents in the study and then presents the main findings of the interviews. A personal reflection is given to provide insight into the research process and observations made by the researcher.

The aim of the study was to explore the experiences of people who receive swallow therapy following surgical treatment of head and neck cancer by meeting the following objectives:

- To explore the experience of people undergoing surgery for treatment of head and neck cancer.
- To explore the experience of people with swallowing difficulties following surgical treatment of head and neck cancer.
- To explore how well prepared people are for the effects of surgery on their swallow competence.
- To explore the experience of receiving dysphagia therapy from a speech and language therapist.
- To understand the components of effective or non-effective therapy from a patient's perspective.
- To inform the development of optimal swallow therapy interventions.
- To develop a therapeutic intervention model for people who have dysphagia following surgical treatment of head and neck cancer.

The participants

Fifteen people took part in the research. Each person had undergone surgical treatment for head and neck cancer and had reconstruction of their mouth using skin, muscle and or bone from another part of their body (see appendix F). The following section gives an introduction to the people who were interviewed to help understand the context of their contributions. All names are pseudonyms.

All interviews except one took place in the hospital, in a quiet room on the ward without interruptions. One participant asked that he emailed his responses to the interview questions. The interviews took place from day 7 to day 14 post surgery. At this point in their recovery the individuals were not requiring strong pain control or significant nursing support; they were all independently mobilising around the ward.

Table 4 Descriptive statistics

Description n=15	Value
Average age	Median: 62.8 years Range: 48-75 years
Gender	M: 8 F: 7
Surgical intervention	Reconstruction of mandible: 7 Reconstruction of maxilla: 3 Reconstruction of tongue: 4 Reconstruction floor of mouth: 3 Tracheostomy: 15
Type of reconstruction	Fibula flap: 4 Radial forearm free flap: 6 Antero lateral thigh flap: 2 Scapula flap: 1 Deep circumflex iliac artery: 2
Average length of stay	Median: 13 days Range: 21-9 days

Mary

Mary was 68, married and retired, with no children. Mary had worked in a busy client facing role before she had retired and she described how communication with her friends and colleagues had formed an important part of her working life. Mary hadn't had cancer before but had spent time in hospital as a result of other physical health problems which pre dated her head and neck cancer surgery. Mary underwent tracheostomy insertion, neck dissection, a maxillectomy (removal of the roof of her mouth), orbital floor resection and reconstruction (removal and rebuilding of the floor of the eye socket). The cancer and surrounding bone that was removed from her face was replaced with a titanium plate along with skin and muscle from her thigh (an anterolateral thigh flap). Mary was in hospital for seventeen days before she was discharged home.

Annie

Annie was 75 years old, retired and widowed, and had two supportive children who visited whilst she was in hospital. Annie hadn't spent time in hospital before her head and neck surgery, and she described feeling nervous about how she would cope with the hospital environment. Annie also underwent tracheostomy insertion, neck dissection, a maxillectomy with reconstruction using skin from her forearm (a radial forearm free flap). Annie spent nine days in hospital.

Annie projected herself as a positive person, as she was outwardly cheerful. However she was both jovial and tearful at times during her interview. The interview uncovered her beliefs about how she coped with her surgery, and specifically how she had felt safe and confident in the skills of the clinical team to support her through her post-surgical recovery. Annie discussed the way the clinical team communicated with her and the positive impact that this communication had.

Sandra

Sandra was 63 years old, divorced and retired. Sandra had a close and supportive family whom she spoke about during her interview. Sandra was a grandmother and had spent time supporting other family members through life changing illnesses, which she reported had altered her perception of life and suffering. Sandra seemed stoical, and having also undergone surgery and radiotherapy previously for treatment of head and neck cancer, she referred back to her previous experience within the interview. Sandra had the floor of her mouth and jaw resected, and reconstructed using bone and skin from her shoulder (scapula flap), she also had a tracheostomy inserted. Sandra remained in hospital for twelve days.

Sandra seemed to have developed her perceptions about the hospital team over many years, as she had time since previous surgeries to reflect on her recovery, and as such she provided a different perspective to those who were undergoing surgery for the first time.

Emma

Emma was 63, married with children and in full time employment. Emma had supportive family and friends, however she was very clear that only specific people could visit her whilst in hospital because of her concerns regarding the way she would look. Emma had not had any significant physical illnesses before her treatment of head and neck cancer. Emma underwent tracheostomy insertion, neck dissection, removal of part of her jaw and reconstruction using skin from her leg (fibula flap). Emma remained in hospital for eleven days.

Emma spoke about how life before surgery had been complex and described trauma which had pre dated and framed her diagnosis and was likely to influence her recovery as a result of the psychological impact this had on her. Emma was tearful at times, but was able to describe subtleties about relationships she had experienced whilst was in hospital, along with the potentials and limitations of these relationships to enhance her recovery.

Mike

Mike was 65 years old, married with children in full time employment, and was expecting to return to work after surgery. Mike hadn't had head and neck cancer before this admission, but had been diagnosed with other cancer and had received treatment including chemotherapy. Mike underwent tracheostomy insertion, neck dissection, resection of his jaw bone (mandible) and reconstruction using bone from his leg (fibula flap). Mike was in hospital for ten days before returning home.

Mike described himself as a quiet person, however as the interview progressed he spoke freely and could recall specific moments where interactions with members of the team changed the way he felt

and his experience. Mike seemed to be pragmatic and discussed his recovery in matter of fact terms, despite this he provided insight into the emotional impact of the surgery and how he had felt at various points which had been challenging and overwhelming for him.

Melanie

Melanie was 49, divorced with children and in full time employment. Melanie had undergone previous surgery and radiotherapy treatment for head and neck cancer and breast cancer and discussed this during her interview. Melanie had a tracheostomy, removal of more than half of her tongue, and reconstruction with skin and muscle from her thigh (anterolateral thigh flap). Melanie remained in hospital for eighteen days before she was discharged home.

Melanie seemed to be a relaxed person and took time to consider her responses during her interview. Like Sandra and Mike, having cancer before this admission for head and neck cancer surgery gave her a different perspective on her recovery. Melanie seemed less anxious than other informants and she seemed to recognise elements of the recovery which she could control and influence, and those which she couldn't.

Andrew

Andrew was sixty three years old, retired and married. Andrew had previous cancer before his head and neck cancer surgery; he reported that in some ways he was aware of what to expect. Andrew underwent a tracheostomy, excision of tumour from the floor of his mouth, and had reconstruction using skin from his forearm. Andrew stayed in hospital for twelve days following his surgery.

Andrew was very open during his interview and discussed how the surgery had an impact on the way he could speak and swallow. Andrew also described the impact of his diagnosis and surgery on his family, specifically his wife who had been quite anxious whilst he was in hospital. Andrew discussed his interaction with the SLT and his opinions on the impact that the physical and emotional components of therapy had had on him.

Maria

Maria was sixty eight and in part time employment. Maria had a close family and a strong religious faith which she referred to during her interview. Maria also had a job which required her to use speech and communication with people all day, and as such she was very concerned about her communication. Maria had not had head or neck cancer previously, and had been in good health. Maria had a tracheostomy, neck dissection, resection of a tumour in her jaw, and reconstruction using bone and skin from her leg (fibula flap). Maria was in hospital for twenty one days before she went home.

Maria described how she had felt supported by specific members of staff whilst she was in hospital, and she could describe the ways in which their actions had improved her recovery. Maria described her family and her role within her family, this made her feel emotional during the interview as she considered how this may have been altered by her surgery.

David

David was fifty years old and single, with an extensive social network of friends. He was in full time employment which he expected to return to, and had not had any health issues which caused him to be in hospital before his head and neck cancer treatment. David underwent tracheostomy insertion, resection of the floor of his mouth and rim of his jaw, and reconstruction using skin from his forearm (radial forearm free flap). David was in hospital for eleven days after his surgery.

David was an open person and was very happy to share his experience during the interview. He provided detail about how his reconstruction and recovery had felt, and what his experiences of the hospital, the staff and the surgery had been. David also provided personal information about how he had coped, and ways he may have been optimally supported which he did not feel had happened at the point of diagnosis.

Simon

Simon was seventy three, retired and married with children. Simon had not had head and neck cancer previously, and had been in good health before his diagnosis. Simon underwent tracheostomy insertion, resection of a tumour within his jaw (mandible), neck dissection and reconstruction with bone and skin from his hip (deep circumflex iliac artery). Simon was in hospital for twelve days before he returned home.

Simon seemed to be a private person, and his interview was conducted most quickly within 10 minutes, compared to most interviews which took around 60 minutes to conduct. Whilst he was happy to partake in the interview, he didn't describe his feelings or experiences in as great a depth as other informants.

Steve

Steve was forty eight years old and married with children. Steve was in full time employment and had not had any health issues before his head and neck cancer diagnosis. Steve was very concerned about his function and communication following his surgery, especially regarding its potential impact on his livelihood. Steve had a tracheostomy, neck dissection, resection of half his tongue, removal of all his teeth, and reconstruction using skin from his arm (radial forearm free flap). Steve was in hospital for sixteen days.

Steve's surgery meant that his speech was difficult to understand at times. This was distressing for Steve and he discussed the reality of this challenge during his interview. Steve described his sense of loss during his interview, and his concern at returning home. The interview with Steve was emotionally demanding, as it was particularly sad to hear Steve explain how challenging his diagnosis and recovery had felt. He had many physical problems he was trying to manage, specifically his speech.

Eleanor

Eleanor was seventy three, married with children, and retired. Eleanor had not had previous head and neck cancer treatment. Eleanor underwent tracheostomy insertion, resection of her tongue tumour and reconstruction with skin from her forearm (radial forearm free flap). Eleanor remained in hospital for twelve days.

Eleanor had not grown up in England, and she described how challenges she had faced as a young woman had created a strong sense of determination within her. Eleanor explained how services could have been delivered differently to improve her experience in hospital, and how her family and daughters had supported her after surgery. Her daughter attended the interview.

John

John was fifty three, married and recently retired. John had not had any notable ill health before his diagnosis of head and neck cancer. John underwent tracheostomy insertion, neck dissection, removal of the roof of his mouth (maxillectomy), clearance of his lower teeth and reconstruction using bone and skin from the hip (deep circumflex iliac artery). He was in hospital for twelve days.

John was a quiet and private person, who spoke in detail about the practicalities of his surgery and the process he had gone through. John became unexpectedly emotional at points during his interview when describing the interventions he had received. John had found his time in intensive care particularly challenging due to his response to morphine, which had made him feel confused and at times aggressive towards the nursing staff. He also struggled with the presence of his tracheostomy.

Edward

Edward was sixty, married and in full time employment which he expected to return to. Edward's job required him to speak publicly in high pressure environments. Edward had not had previous diagnosis of head and neck cancer, and had not spent time in hospital before his surgery. Edward underwent tracheostomy insertion, neck dissection, removal of half of his jaw and reconstruction with bone from his leg (fibula flap). Edward was in hospital for fourteen days.

The nature of Edward's job meant that he was used to describing and explaining complex issues. This enabled him to provide detailed insight into his experience and his interactions with health care professionals.

Siraj

Siraj was seventy one, married and in full time employment. Siraj also had a busy job which required him to communicate with numerous people from varied backgrounds on a daily basis. Siraj had not undergone previous head and neck cancer treatment. He underwent tracheostomy insertion, neck dissection, partial tongue removal and reconstruction with skin from his forearm (radial forearm free flap). Siraj was in hospital for ten days.

Siraj was the only informant who asked that he typed answers to his interview questions, rather than partake in a face to face verbal interview. Siraj explained that he felt more comfortable emailing answers to the questions because of his speech challenges. It was also of interest that Siraj felt he had not received enough speech therapy from the SLT, which may have contributed to his reluctance to partake in a face to face interview.

Most interviews took around half an hour to an hour to conduct, and around eight hours each to transcribe. Some participants became tearful when discussing their time in hospital and the impact of their surgery, but no participants took up the offer to meet with the clinical nurse specialist or counsellor after the interview.

Themes

The themes, subthemes and categories which emerged from the data captured the lived experience of the physical, emotional and social elements of head and neck cancer surgery. Whilst many questions within the interview schedule focused on exploring what the swallow therapy intervention entailed and the role of the SLT, discussion with informants moved beyond the confines of this topic. The interviews explored concepts about how people felt and about their interactions with the whole team. Following transcription two overarching themes were identified;

- 1) I never dreamt
- 2) They look at you and they speak to you

The first main theme, 'I never dreamt', explores the enormity of the symptoms and changes people experience when undergoing surgery for head and neck cancer and the difficulty of being able to prepare for the reality of what will happen. The second main theme uncovered key components of effective relationships with health care professionals following surgery. The main themes are made

up of subthemes and categories (table 5) which were named using direct quotes from the transcripts, as this ensured the interpretation remained close to the data and was representative of the things people described during the interviews. Appendix G includes data which informed the theme generation. A lack of preparation and coping with the shock of diagnosis was still being felt when a person was describing their physical symptoms following surgery. When reading the following themes it is important to remember that these issues did not happen consecutively, independent of one another as the presentation of the information suggests. In reality this was a messy and tangled group of experiences and thoughts which people described at a vulnerable time when they were still on the inpatient ward following their head and neck cancer surgery.

Table 5

Main themes	Sub themes	Categories
I never dreamt	'like this for the rest of my life'	'Voicelessness'
		'Just soft flesh'
		'How I look when I talk'
	'you just do it'	'No choice'
		'Search for strength'
	'It's a journey'	'How rough it would be'
		'you come out of it'
They look at you and they speak to you		'you're not going to take this on board'
	'You've got to be able to connect'	'that people have the time'
		'they really want you to get better'
	'I felt like a human being'	
	'You'll find another way'	
	'Give me your life into my hands and I'll look after you'	

I never dreamt

The main theme 'I never dreamt' began as a set of categories which were collected together into subthemes and enabled the theme to emerge. The main theme 'I never dreamt' overarches the spectrum of different experiences people described following surgery including not being able to talk, looking different, the challenge of recovery and the journey that accompanied their surgery. People were fundamentally altered, their physical-self changed along with their abilities to carry out everyday tasks which enable a person to have autonomy. These tasks included being able to eat and drink normally, talk to their family or friends, and be out in public without feeling embarrassed. A person's swallow and speech became a symptom of the impact of surgery rather than a feature of

self. This theme identified that the notion and the reality and impact of surgery were very different things.

'and I knew like they had taken a bit of my arm to put in my mouth but I didn't know the extent of what was happening I didn't know whether that my mouth would end up like it is' (David line 43)

This theme also identifies the importance of recognising that regardless of the attempt at preparation made by the clinician, the individual is likely still to struggle to cope with the enormity of head and neck surgery. The following sub themes and categories explore components of these phenomena in greater detail.

Like this for the rest of my life

This subtheme 'Like this for the rest of my life' is made up of three separate categories:

'Voicelessness' 'Just soft flesh', and 'How I look when I talk'. This subtheme is central to the findings as it identifies and draws together the physical and existential elements of the impact of, and reaction to, head and neck surgery. People recognised they were losing the person that they had been. Parts of their body were being replaced with 'flesh' and when they tried to communicate as human beings they were acutely aware that people related to them primarily because of the way they looked rather than because of what they wanted to say. The permanent nature of these alterations was obvious to the individuals. Not only were their lives changed for ever, but the person that was had gone.

'at the beginning I felt that was the end of my life' (Maria line 42)

Voicelessness

This category, 'voicelessness' explores how informants described their frustration and challenge at having no voice after surgery. Ultimately this voicelessness was transient, as once the tracheostomy was removed the individuals were able to speak again, however the fear of not being able to speak again was still real to the participants at the point of interview.

'The worst part erm immediately post-surgery was being locked in your own body not being able to converse' (Emma line 215)

People described being physically unable to speak, whilst feeling locked in, being misunderstood and frightened at the potential of never being able to speak again. The uncertainties about long term function following surgery also resulted in feelings of vulnerability and frustration. Steve described his concerns which involved losing his job, partly due to being unintelligible. Steve was processing the realisation of this change and reality in the post-operative phase, and described it during the

interview. The transition from pre to post-surgery was notable, Steve had a job and could talk before his operation, and then within days he was jobless and couldn't talk. He had lost the parts of his life which were what he did and who he was because of the way he now spoke.

'I've lost my job now anyway but it's just my mouth is the main, that's the tool box for me, if they can't understand me then, [1 second] I don't know, er what will I do with that one' (Steve line 64)

'I wondered if I'd ever get my voice back to how it was before' (Mary line 199)

'can you imagine me to feel not be able to speak ever again cause that's what I thought, I thought it's just a pen and a paper' (Maria line 46)

These experiences were happening whilst people were still processing their diagnosis, experiencing shock at the post-operative symptoms, and recognising that their bodies had been extensively altered by surgery.

'you've got your own voice, to voice your opinion, it's hard not being able to talk, put somebody that can talk, like yourself in the position for two or three days and tell 'em they can't talk at all [3 seconds] its strenuous' (Sandra line 403)

There was a sense of great anxiety and trauma associated with the description of being voiceless, this was a frightening time for the participants. Sandra explained that the challenge of the post-surgical phase was not person specific, that the cancer and the effects of the treatment were non-discriminatory. The words Sandra used suggested that with the loss of her voice, came a loss of independence and the opportunity and means by which she could state her opinion. She lost some fundamental components of what made her the person she was.

'it depresses you sometimes, you know, you could talk and now you can't' (Eleanor line 49)

Just soft flesh

The category 'Just soft flesh' explores the impact of the physical changes informants experienced as a result of their surgery. David, Emma, Maria and Sandra discussed in detail the feelings of having surgery within and around their mouth and the way this altered them. There seemed to be a transition from where body parts were clearly defined, named and belonged to the individual before surgery, to the post-surgical phase where they were no longer defined body parts, but had become just "soft flesh". Furthermore, the sensation had altered, the tissue felt numb and so enhanced the feeling of not being able to integrate part of the body or person.

'I mean my ear feels like it doesn't belong to me it's just it kind of hurts' (Emma line 200)

'this side just feels like nothing at all it's just soft flesh' (Maria line 122)

The word 'belong' is of particular interest as it underlines specific changes a person may experience, both a change in ownership and perception of one's own body and skin. Emma explains that her ear is now just a conduit for pain symptoms and doesn't feel like it belongs to her. Maria refers to her mouth as 'it', rather than 'my', which suggests that her reconstructed mouth didn't feel part of her own body. It is interesting to note that Maria also uses the word flesh, without reference to the bone and skin used from her own leg to reconstruct her mouth. The word 'flesh' has unpleasant associations, perhaps more frequently used in context of decay and lacking personhood. These changes in a person's sense of ownership and perception are subtle, but together have the potential to contribute to a feeling of loss of control of the body.

David used simile and deliberate terminology to describe what his reconstruction felt like to the interviewer who was unlikely to understand the reality of the surgery,

'it feels like I've got er raw sausages in my mouth' (David line 47)

This description is vivid, and has negative connotations. It is similar to Maria's description of soft flesh within one's mouth. This information sheds light on the reality of what having an oral reconstruction feels like, alongside the reconstruction not looking like or behaving like one's own face, it may also be unpleasant and feel alien to the individual. Sandra recognised that she looked different, and described looking like Frankenstein; however she framed this within a positive context of being alive and breathing.

'I don't care whether I'm like metal mickey, Frankenstein, I'm alive and breathing and glad to be here' (Sandra line 388)

Not all informants felt as positive about their appearance and function, there were divergent reports.

'it's just horrible that I've got to be, I get on with it so, I will just get used to use my mouth, erm, I don't know it's just the problem with this stuff coming [gestures to saliva in mouth]' (Steve line 74)

Steve struggled with being, feeling and looking different and had less positive feelings than Sandra. Being alive didn't seem to abate or mitigate his feelings of frustration when attempting to manage his excess saliva, as he lost control of his altered body. People experienced the height of these changes in their physical being at particularly difficult time, when they had a tracheostomy and were unable to effectively communicate their concerns. The following category explores the impact of these compounding issues.

How I look when I talk

People reflected on what they looked like, how they saw themselves and how they believed they appeared to others. Not only was this difficult in itself and the image that they presented to the world, but it also had an impact on the way that they believed people would interact with them in the future in both verbal and non-verbal interactions. The effects of head and neck cancer disrupted their social experiences. This category, 'how I look when I talk', encapsulates the challenge of how basic communication had changed. Their efforts to talk and engage in social discourse were accompanied by significantly altered appearance which drew attention to the way they looked rather than what they were trying to say.

Emma explained that it wasn't just her altered speech that was challenging, but also the way she looked when she spoke,

'so I sound a bit strange as well it's the talking as regards to yes I can talk erm but how I look when I talk' (Emma line 195)

Edward also reflected on what people's perceptions of him may be as a result of how he appeared to them,

'I mean people may think oh my god [laughs] if I look like that I'm not going to have that operation' (Edward line 71)

'I am not going to want to go out and see people if I'm going to look like this for the rest of my life' (Emma line 131).

The cosmetic effects of the physical alterations people experienced were challenging to manage. It seemed that there was no way participants could avoid looking the way they did, or to escape the perceived judgement from the outside world. Their issues were exposed through the way they looked, the way they spoke, and the way they looked when they spoke.

You just do it

This sub theme, 'You just do it', comprises two categories, 'No choice' and 'Search for strength'. The theme explores the lack of autonomy or choice making people felt they had about having surgery, and the ways people attempted to manage this issue.

No choice

The informants described the lack of choice they felt they had with regards to undergoing surgery. They were able to describe a sense of futility with the disease and potential treatment.

'I didn't really have a choice, it's go and have it done [crying]' (Emma line 145)

'I know I didn't have any treatment left to me, if I didn't go for, that was radiotherapy and that is not cure that is only for to stall things and give you a bit more time' (Mary line 73)

'if it's got to be done it's got to be done' (Simon line 204)

The lack of choice seemed to coexist with a sense of loss of control, in the way informants looked and functioned. The participants reported that they had little choice regarding whether they would have the operation, and then a lack of control over the way their bodies functioned afterwards. No informants described having a choice and actively choosing to have surgery.

'First of all I had no choice' (Siraj line 27)

In this quote, Siraj made clear that there was no alternative for him, that surgery was his only choice. This framed his experience. Six people discussed this issue in detail. Informants tended to mention this lack of choice when they were asked how they were feeling after their surgery. Lack of choice reappears in later themes and was a thread through these experiences of head and neck cancer surgery. This lack of choice seemed to affect the individuals' sense of power and autonomy, and ability to augment or change their situation before or after surgery. There was little they could do to change the situation they found themselves in.

Search for strength

The 'search for strength' sub theme explores how individuals tried to find a way through the post-surgical process. Participants discussed ways that they coped and attempted to manage the life altering transition following surgery. The search for strength was an individual process. Participants explained that health care professionals had not helped them create or utilise this strength; this ability seemed innate and was a result of either beliefs or personal coping strategies which pre dated the cancer diagnosis.

For some people strength involved deciding to deal with issues as they presented, and moving through time moment by moment, rather than considering and analysing their coping strategies. This may have been due to a sense of lacking choice regarding the disease and its treatment. For others, their response included active processes such as engaging with religion and praying, or using drugs and alcohol. Some people described the sadness associated with their treatment, and the way it made them feel.

'I felt terrible' (Melanie line 104)

Others described how their relationship with a spouse or respect for a parent, or sense of responsibility formed the basis of why they underwent surgery, and the way they searched for strength.

'I could, if it wasn't for [husband]...I could have left the op' (Emma Line 101)

'my mother didn't struggle to give birth to me, to struggle to put clothes on my back for me to give up' (Sandra line 347)

Sandra's quote also uncovers what prepares or enables people to cope with the situation they find themselves in post-surgery. There seemed to be a sense of pride associated with digging deep and managing the physical and emotional effects of the surgery. This may have originated from Sandra's relationship with her mother, or her own sense of achievement at getting through the post-surgical phase. The following extracts identify a spectrum of different responses people had to their diagnosis and treatment.

'I put faith in my God who has pulled me through and bought me back safe and sound' (Siraj line 29)

'I'd given up drinking but I went straight to the pub and got hammered, got off me tits you know' (David line 462)

Other people couldn't describe what had given them strength or even whether they were feeling strong.

'I don't know really it hasn't really sunk in, I don't know, I've thought about how I've done when I've been in here' (Steve line 71)

This category demonstrates the various modes of coping which people may adopt either actively, or as a passive response. For Steve coping also involved making sure no-one else knew that he was unable to pronounce his daughter's name, and controlling his language to mask this lack of ability.

'she knows but nobody else knows, but I just can't say the letters of half her name, with that word, it's hard' (Steve line 264)

Mary explained that she needed to recover to maintain her independence, which she knew had the potential to be lost following the surgery. She had a pragmatic realisation of the things that may be put at risk as a result of head and neck cancer surgery which she described in her interview. A sense of vulnerability at the prospect of loss underlies the following quote.

'I didn't want to lose my independence whilst I've got it' (Mary line 137)

'the nurses, the doctors, everybody helped me a lot I couldn't have wanted any better' (Eleanor line 61)

There was recognition of the support from the clinical team as described by Eleanor, however the individual's impetus, focus and strategy to search for strength seemed to be self-generated. In some cases this was borne from previous struggles or through facing challenging circumstances that prepared individuals to face this diagnosis and treatment. It became the core component of how they coped with their post-surgical recovery. This finding is important as it identifies a resource generated by the individual rather than an outcome facilitated by the health care professional, and raises questions about whether this ability could be developed or optimised by the health care professional to improve a person's post-surgical experience. This will be considered further in the discussion chapter.

This sub-theme provides insight into the ways people attempt to cope with the effects of head and neck surgery. Beyond the physical compromise, the way a person views themselves and considers what he/she is intrinsically may be altered, which is challenging and requires the individual to adapt and manage difficult realities. The change in the way the individual functioned and viewed themselves demonstrated in 'Like this for the rest of my life' influenced how and why they needed to cope, which was explored in the sub-theme 'You just do it'. This change also influenced what people needed from the health care team, and the parameters by which they measured their recovery. This is exposed in the following sub-theme, 'It's a journey'. People didn't describe or relate their coping to the surgical intervention or biological recovery. It wasn't the size of the wound that required a search for strength, it was the holistic impact and total insult of the surgery which affected how the individuals could be independent, or converse with their children.

It's a journey

This sub theme, 'It's a journey', refers to recovery post-surgery, which the informants explained was complex. The meaning of recovery didn't pertain to the biological condition, and it therefore couldn't be simply measured by biological improvements. People described the fluctuations they experienced after surgery, where they didn't feel human or lay in bed feeling wretched. Participants recognised that each person's surgery and reaction to surgery would be different, and that at various points this recovery would change and develop. The experience of the post-surgical phase was difficult and turbulent, but people had a sense that they were moving forward, and improving. Informants described the journey they experienced. The categories within this sub theme describe this journey in more detail.

'obviously you're a bit more traumatised than you think you will be' (Andrew line 34)

How rough it would be

This category 'How rough it would be' covers how difficult surgery and the recovery was in both physical and emotional terms. In this category people didn't describe their experience using medical terminology which marked improvements in function, as a clinician would. People used words like 'adjustment', 'trauma', 'journey', 'normality' and 'exhaustion'. The term recovery encompassed getting through and moving from one phase to another after surgery, whilst being accompanied by a range of difficult physical and emotional experiences.

'I knew it was going to be a long fight but I didn't realise how rough it would be' (Mary line 108)

'I lay there and I just feel so wretched' (Emma line 247)

'I will have down moments and I'll probably go home and cry my eyes out' (Emma line 388)

The disease and its treatment resulted in people feeling overwhelmed, crying and feeling wretched. Recovery was not linear or predictable. The only certainty seemed to be that no one else could understand what the participants had gone through. Mike explained the nature of head and neck cancer, which was person specific and beyond the capability of an average person to comprehend.

'Mr average in the street don't know a thing' (Mike line 237)

You come out of it

'I'd never thought of this point of it or part of it being like a journey but it is a journey' (Mike line 283)

In this category, 'You come out of it', some people were able to express that despite the hard times, there is a change and a future. They could have positive expectations about their future function and potential, and recognised that things were getting better following their surgery. Participants appeared to realise that with the passage of time and healing things could get easier.

'I know it's going to take months really but it'll be like day after day, week after week you know what I mean and then there will come a time where ill I think it will be so gradual that I probably won't notice, you know I won't be able to go oh you know, cause it will be so gradual' (Melanie line 309)

Some participants could determine what they were likely to achieve and at what pace, they also recognised that progress may take months.

'the body adjusts' (Emma line 108)

A sense of transition was also noted in interviews with informants, specifically when people used phrases such as the following,

'I said when I came in, I came in on the dark side and I'm coming out on the light side, and it's happened' (Annie line 150)

The overarching theme 'I never dreamt' established that people experienced more than physical symptoms. Informants described the trauma and challenge they faced as a result of communication issues and the gradual change they expected over months. One person also discussed how they had moved from a dark phase to one of light, indicating a sense of positivity and hope. Only one individual used the phrase 'cure'. For the majority of people, this transition involved a costly journey and dramatic changes to their physical self because of their cancer treatment. These physical changes also had existential implications for their ability to continue the lives they had before. The end point of their transition was not defined by simply being cancer free; it seemed to be around achieving what would be a good and meaningful life.

'people will say well at least you're alive, yes but I want to be alive in the best way I can' (Emma line 100)

You're not going to take this on board

This category, 'You're not going to take this on board', covers people's lack of readiness for what was to come after surgery. Participants were asked directly whether they felt prepared for the effects of the surgery they had undergone.

When asked how prepared they were, participants acknowledged some value to the pre surgical meeting with the clinicians, specifically the opportunity to meet the multi-disciplinary team and to discuss what was going to happen to them. Some people could recall the names and job roles of the people they met however most of the participants did not mention the team members by name. Participants were clear that the meeting didn't prepare them for what was to come. Individuality, the nature of the diagnosis, and the limitations of words acted as boundaries to being able to prepare people for the reality of the post-surgical phase. Beyond this, the individual's sense of personhood had been altered. The previous sub themes about being voiceless, feeling like there was soft flesh in their mouths, and alterations to the way a person looked illustrated this. The effects of surgery were far reaching and personal which meant that even conceptually attempting to prepare a person was problematic.

"you're not going to take this on board [1 second] you're not, you won't" (David line 29)

"I don't think you can, I don't think you can prepare people er by just sitting down and saying well you're going to experience this and this is a consequence, yeah you hear the words and er I think it's

important to go through that, that erm er that process but obviously er until you've done it it doesn't mean very much' (Edward line 53)

In this extract, Edward explains that whilst a person may be physically able to hear words and information about the impact of surgery, these words alone should not be considered preparation for the post-surgical phase. He describes the difference between preparing someone for the operation they are about to have, and attempting to prepare them for how they may feel, react or respond to this surgery. The symptoms and biology of the intervention were different to the experience and effects, which move beyond physiological processes. Whilst symptoms could be predicted, the ways in which this might affect individuals could not be predicted. Melanie explains that the pre-operative discussion may simply provide the person with a 'rough outline' of what may happen.

'they can't tell you what is going to happen to you definitely, but they give you a kind of a rough outline, which I can't expect any more' (Melanie line 165)

It wasn't that people didn't have any preparation, but rather that there was a limit to how prepared people could ever be for the physical and emotional effects of surgery. It seemed that informants were still trying to process and understand what their diagnosis meant.

'I wasn't prepared at all, because it was only two weeks from finding out, to do it' (Maria line 72)

Informants recognised that there were limits to what they could be prepared for, and they described how the realities of the unforeseen physical and emotional symptoms were challenging to cope with.

'I don't think anything could prepare you for this, no, but they've all reassured me it will get better' (Steve line 203)

The reassurance people received from the SLT, surgeon and nursing staff regarding expected recovery, and progression from the immediate post-surgical phase was important. It provided them with support during their unexpected transition where they functioned, looked and communicated altogether differently.

They look at you and they speak to you

The second main theme, 'they look at you and they speak to you' explores the communicative experience that participants had with the SLT surgeon and nursing staff, the relationships that formed whilst they were in hospital and the impact this had on their recovery. The first main theme exposed the effects of the surgery and the challenges that this posed to the individual in physical,

emotional and psychosocial spheres. This second main theme explores how interactions and interventions from the team changed and influenced these experiences. The voicelessness people experienced was met with being looked at and spoken to by the clinical team. This enabled them to engage in communication when their physical ability to communicate was diminished.

This overarching theme is about how the health professionals interacted and communicated with the person, rather than their altered and disfigured face. The theme considers how validating it is to still be spoken to as a person and not as a wounded body. The subthemes within this main theme are, 'You've got to be able to connect', 'I felt like a human being', 'You'll find another way' and 'Give me your life into my hands and I'll look after you'. The categories include, 'That people have the time', and 'They really want you to get better'.

You've got to be able to connect

'You've got to be able to connect' explores the communication experiences that people had with the surgeon, the SLT and the nursing team. People didn't describe the communication skills of the professional, they described how it felt to be communicated with. Discussions with the clinicians offered people an opportunity to be normal, when the participant's face, swallow and speech were not normal. This sub theme explores the team's ability to communicate with the individual, and have the skills to overcome, or look past the physical changes people had. To be communicated with as a human being enabled people to feel like they had the potential to recover to a more human state. The way the team behaved and interacted was a vehicle for meaningful interactions, and supported participants to create relationships with key members of the team, specifically the SLT ,surgeon and nursing staff. As an overview, the SLT seemed to offer the individual space to describe and explore their altered function and self, the surgeon seemed to provide time, recognition and acknowledgement of the reality and enormity of the surgery they had undergone, and the nursing staff reassured and provided support and care to the individual. These attributes were not profession exclusive, and people frequently used the term 'team' rather than naming specific roles or individuals. The collaboration and input from the clinicians seemed to be healing and of great importance to the participants' recovery.

'you're not just there to give someone their medication, to take their blood pressure and you know you've got to be able to connect' (David line 304)

That people have the time

The necessity of health professionals spending the time needed to have a meaningful interaction with people was identified as an important factor in an effective therapeutic relationship. Participants attributed value to the duration and time a health care professional was willing to give

them which made them feel valued. The appropriate use of time ensured that health professionals were able to identify people's needs and respond to them, rather than working with a predefined agenda or making assumptions about what a person could do.

'we took a lot of their time that day they were all, nobody looked at the clock' (Emma line 283)

'he's just so nice, calming, relaxing they all are they make you just feel at ease, he's been brilliant, hundred, hundred percent you know I'll have to, yeah I'll really remember him, I owe him a lot, he's given me he's given me that confidence and time' (David line 369)

Of interest was the recognition of the space and time provided specifically by the SLT.

'I mean if they'd just gone up to me and said here's a glass of water and walked off I'd have, well I wouldn't have known what to have done as silly as it sounds' (David line 86)

'you can't just go to a person's bed and talk to them and just say about the speech, you've got to get them for at least a half an hour or an hour and really sit and talk with them you know and reassure them that you can find what they need to do and then see if they can do it' (Eleanor line 368).

There were also examples of when participants felt they hadn't been given adequate support and the impact that this had. Siraj explained that he felt his speech may have been better if he had seen the SLT more frequently, which didn't happen.

'I still feel that I should have been given lessons by the speech therapist because she felt that my speech is good, she decided not to give me any further advice' (Siraj line 60)

This extract provides insight into the frustration Siraj experienced as a result of his needs and perceptions not being managed or acknowledged optimally, and the effect this had. Participants could recognise when they were given sufficient time and space, and the value of this. They were clear that the time, alongside the interventions provided within this unit of time, were important to their recovery. It wasn't just the time itself, it was the adequacy of the time when used in a therapeutic way that had value. Eleanor explained that she felt in order that repetition of learning could take place for her swallow therapy, she needed to see an SLT for at least half an hour, and Steve suggested it should be once a day. However they did not attempt to delineate how much time was required to connect with them. The time associated with connecting with the individual was more complex and related to the clinician's ability to create space to acknowledge, understand and be with them as a human.

'you've got to balance these differences of the job haven't you you you've got to convey to people a realistic and accurate erm perception of what's wrong with them and what their expectations are erm, and you've erm at the same time on the human level and the psychological level er you you don't want to give the impression that whatever you do they're going to drop down dead in the next six months' (Edward line 89)

They really want you to get better

'they've been so nice and helpful and kind and you know as if they really want you to get better'
(Simon line 155)

This category 'they really want you to get better', describes how the interactions informants had with the team made them feel. This communicative experience itself seemed therapeutic. People didn't describe the content of discussions as much as the sense and feelings they received from the communication. The style and openness in which the communication was offered was of most value to the participant.

'whoever came to me and did whatever they did, were were kindness itself' (Annie line 46)'.

'It's absolute generosity' (Maria line 99)

'I am deeply touched by the way I was treated and looked after' (Siraj line 31)

'as people asked me questions I'd sort of answer it and I'd answer it and she'd (the SLT) give the the same answer but her answers were absolutely a hundred percent smack on with what what I was trying to say, yeah an if it weren't quite right then I must of given a gesture or a nod or a shake and she'd change it an to exactly wha what it was [begins to cry] I only met her for a couple of minutes [crying] but really yeah but she was a really really big help' (Mike line 138)

The sense of empathy and understanding from the SLT is clearly identified in this extract. Mike describes the iterative process and co-creation of communication between the SLT, surgeons and participant on the ward round when this experience happened. His feelings were derived from a complex communicative experience, where Mike used eye contact and body language to convey his aims and intent which the SLT was able to interpret.

The identification of the skill of the SLT to listen and understand the participants was clear within the transcripts. Informants used words such as 'genuinely interested', 'thoughtful' and 'caring'. Some discussed the practical interventions they were provided with from the SLT, such as supporting with swallow or speech which is discussed in the sub theme 'you'll find another way'. However, it was clear that therapeutic discussion encompassed more than physical rehabilitation. People described

receiving a balanced view of how the operation went and the impact on function, along with feeling understood and listened to. The ways in which these interventions may be replicated are considered in the discussion.

'for me I responded to her and her attitude' (Emma line 60)

I felt like a human being

This sub theme, 'I felt like a human being' explores the impact of the communication experience, the result of being given adequate time for assessment, therapeutic input and reassessment, and the effect of feeling as though the team were investing empathy and care into the participant's recovery. People described how clinicians made them feel human and the importance of not being reduced to a hospital number or diagnosis. This sub theme begins to explore what being human means, and the importance of this after a surgery which may strip a person of this essential sense.

'because if they get talked to properly like everybody has talked to me properly, as a human being, as a person, shown me lots of kindness' (Sandra line 307)

'I didn't feel like a number, I felt like a human being' (Annie line 194)

The quotes suggest that being made to feel human involved being considered valuable enough to be treated with kindness, being spoken to in a respectful or appropriate way and being recognised as an individual rather than a number.

'what does help is to know you are not just a patient stuck in a bed you are still a person and they show caring and that I think goes a long way for most people' (Emma line 372)

The vulnerable sense of personhood was established in this sub theme. People recognised how feeling cared for by the clinicians helped them to recover, and feel more than a patient. The sense of being human was created by being treated in a human and compassionate way. The words 'patient', 'hospital bed' and 'number' provide insight into the way people may feel stripped of their identity and sense of self, and can be reduced to a component of the surgical process. The way in which the team communicated with the individual and their interactions prevented this from happening.

'the way they spoke to me, the way they explained things' (Sandra Line 166)

This theme also relates to the sub theme 'just soft flesh', where informants felt their bodies and skin no longer belonged to them. If participants were feeling less than human, being treated like a human may have been the fundamental key to their recovery, sense of self, wellbeing and ultimate ability to function in society. This concept raises further questions about what it means to be human, how

individuals lose or gain this sense, and how the actions that the health professional performs may help someone to feel more human following surgical treatment of head and neck cancer. This will be explored in the discussion.

You'll find another way

This sub theme describes how the swallow rehabilitation from the SLT enabled them to explore different ways of doing things that had once been done without thought, such as eating and speaking. Participants discussed what the SLT provided and the nature of the intervention. The time with the SLT included assessment of swallow, therapy to improve the swallow function, and advice and support. Informants described this in the following ways,

'that practical advice has been has obviously been valuable and I think will continue to be useful because you know one doesn't...I've never done, had this before so you don't know what to expect on a day to day basis and how best to manage with practical things like eating and how eating is affected by the developing scenario in the mouth' (Edward line 40)

This extract identifies components of what a therapeutic intervention may mean to an individual. Firstly the sense of ongoing challenge Edward faces regarding his fluctuating ability to eat and drink effectively provides insight into what having a swallowing problem may feel like and the role of the SLT in this situation. There is a vulnerability associated with his new physical challenges which Edward hasn't experienced before. An expectation that the SLT can and will manage the ongoing practical problems and the accompanying emotional uncertainty underlies this.

'they told me about the best part to, er the best part of the tongue and mouth to swallow with before swallowing' (Steve line 33)

Steve explained that the SLT had provided him with advice to enable him to swallow effectively. The therapy he received didn't just provide him with ways he could eat and drink. He describes skills he was given to manage his surgically altered mouth, an understanding of how to prepare for swallow, and a recognition of his altered anatomy following input from the SLT. This means more than physical ability. It could enable Steve to feel more in control of his physical self, to re-establish a sense of autonomy, and engage more effectively in meal times and public eating and drinking.

Other people also described what the assessment from the SLT included, such as progression from one type of food consistency to another more complex. The following quote from John explains his reassurance that the SLT understood the food and consistencies of the food she was prescribing. John seems to describe a trust in the SLT as a result of her knowledge base and competence.

'I think she did make me feel better saying I could go from the puree to the mashable, I think she understood the diet' (John line 82)

A sense of recovery of emotional wellbeing and moving forward can be interpreted from this information about the impact of the practical support people received from the SLT. Progress measured in eating and drinking improvements had emotional benefit, and helped people to recognise components of their recovery.

The following quote from Eleanor recounts therapy from the SLT. It exposes how the SLT has the ability to make what is a very complex physiological intervention to improve swallow seem normal and everyday. The SLT avoided the individual feeling overwhelmed anxious or concerned about their swallow or the therapy required to improve it.

'because with the speech therapist it's like oh you're going for an exercise today' (Eleanor line 421)

The information from the participants moved beyond simply what therapy the SLT had provided, to the way in which the swallow therapy was provided.

'talking things through and answering questions' (Mary line 298)

Mary describes how the SLT created a relationship with her, by sitting at the bedside and providing her with space and time to ask and answer her questions. This also resonates with the 'feeling like a human being' theme. The SLT helped Mary to feel valued by giving her the opportunity to discuss and voice her questions.

'but they can gauge each patient that they meet which says a lot, it is all very interesting' (Eleanor line 285)

The SLT provided therapy which included exercise, education and information giving, whilst supporting the individual to feel that they had received a personalised intervention, specific to their needs. Importantly this enabled the individual to feel valuable and gave them a forum to discuss the reality of what a swallowing problem meant to them. The support was iterative and developed as time and their recovery progressed. There was a flexibility and responsive nature to the therapy.

'It was just a very basic are you alright and it got a bit more complicated, I've been told certain more things you know as times gone on' (Melanie line 68)

Whilst the intervention from the SLT provided people with ways and means to improve their swallow function, the effects of the intervention had a greater impact than just physical improvement. Informants described the effects of the intervention:

'I was given confidence you know I swallowed and it was a big thing to me' (Annie line 225)

An important part of this swallow intervention was the ability of the SLT to understand and interpret disordered speech. Without this clinical skill the SLT would not have been able to develop and build the clinical relationship which facilitated the therapeutic process. It is also essential to recognise the fundamental importance of the SLT having a sophisticated level of clinical knowledge and skills. The SLT's skills included the ability to tailor and adapt approaches to the individual which enabled the person to feel confident that they were being given personalised treatment. The key effect of these clinical attributes is the resulting confidence that this high level of skill brings along with personalised assessment of need.

Give me your life into my hands and I'll look after you

This sub theme 'give me your life into my hands and I'll look after you' suggests a safe space was created for people whilst they were vulnerable in this specific stage of transition post-surgery. This experience may represent a liminal space where people are no longer the person that they were and are not yet the person they will be beyond discharge from hospital. It is a space where normal rules do not apply, and the rest of life is on hold. The individual is enabled to devolve responsibility for their care and the health care professional takes on this role. It is likely that this is not time limited, and that people may require this safe space beyond their discharge home, however this has not been explored within the confines of this study.

People described the safety of the ward environment and the staff that supported them. Steve was able to describe his concern at leaving the ward, where it seemed he felt safe and comfortable with the staff who were capable and au fait with his post-surgical changes.

'I'm not going down stairs 'cause I'm embarrassed at the moment about the way my face is, but I'm stopping, being on the ward, but I'm alright' (Steve line 178).

This insight is valuable as it also identifies the security that the ward environment may provide to people who feel vulnerable. Steve no longer feels comfortable being in an open social environment where he would have been at ease before surgery. It is possible that at this challenging time the ward staff become the people who can see the individual beyond their surgical intervention. The health care professional seemed able to normalise these surgical changes and move past them to communicate with the person, whilst the individual and their family may not have felt normal at all. They lost who they had been and needed time to adjust to this new person. The health care professional is able to look past the surgical changes in a way which the individual and their family may be unable to, perhaps as a result of their knowledge and relationship with the person that

existed before surgery. With this in mind, there is also a potential for people to develop a dependency on the safe haven of the ward, with the staff who are able to cope with and support people at a most overwhelming time in their lives.

Personal reflection

Following the interviews I kept notes and made some personal reflections which informed the way that I interpreted the data. I add some of these reflections here. This reflection is written in the first person, as it considers and explores my own personal experiences during the research process.

Working as a researcher whilst employed as a speech therapist within the institution I was conducting the study in was challenging. I made sure that I did not provide therapeutic interventions to any participants, and I wore non-uniform clothes when I interviewed people, to help delineate my role as a researcher, rather than as an SLT. These subtle, practical adaptations were useful and they formed an important part of the design of the study, however the most challenging experience for me was the interview process which I was not able to prepare for in such a deliberate way.

I consider myself to be a competent communicator and an experienced clinician. I work in a senior role as an SLT and have worked with people with communication and swallow problems since qualifying from University nine years ago. The role as an interviewer was much more challenging for me than I had predicted. During the pilot interviews I discovered I was using poor techniques which may have closed down communication; these involved me telling people they were doing well, reassuring them when they became tearful, and inadvertently closing down threads of conversations which had the potential to be challenging for me to manage, although I realised this only when I transcribed the interviews.

These methods and communication style had a negative impact on the participants' ability to describe their feelings and experiences, but were of benefit to me when the conversation became difficult, or traumatic to hear. Whenever I provide lectures or teaching to professional groups, I discuss the importance of being with an individual and allowing them time and space to discuss their feelings. However, when critically analysing my own communication style, I realised that perhaps it was easier to describe this skill than it was to provide it with authenticity. I considered whether this was the case in many examples of the translation of effective communication skills. The philosophical position and aims of the professional may be very different to their practical application, and therefore the communicative experience of the person who is being communicated with. Whilst reflecting on this conflict between what we perceive ourselves to be and what we objectively provide to people we support, I began to recognise different versions of myself, the clinician and the researcher.

It became clear that at various points these two constituent parts could be in tension. When I was listening as a researcher to a person describe their anxiety or sadness I began to try to offer something back, to placate or support the individual as I would as a clinician. The clinician seemed to be a more protective state when a transaction took place; I received sadness and gave back what I thought was reassurance. As a researcher I simply needed to hear and explore a person's experience. At the emotional points during the interviews I found it difficult to hold the emotion, sadness and fear a person experienced; I wasn't able to give something tangible back as I am accustomed to as a therapist.

I also considered whether the objectivity I was attempting to adopt as a researcher allowed me an alternative perspective. I stopped visualising an end point or outcome of the compromise and changes people experienced with their function and cosmetic appearance. There was not a tangible aim or objective to the intervention I was providing, to rehabilitate, improve or alter what was for some people a devastating experience. Instead I was immersed in a conversation and moment with a person who couldn't necessarily communicate with me as they wished, and yet were willing to discuss such personal and private emotions about their experience. I found it very difficult to expose these experiences and feelings without trying to provide something I perceived as helpful, or giving back to the individual.

As I considered and reflected on this tension, and became more adept at just listening, I recognised a change in the response of the participants. One individual became overwhelmed when considering what life would be like after surgery, realising that everything he had known had changed. When I offered support of the clinical nurse specialist or SLT after the interview, the participant declined, and reported feeling fine, the interview had been enough.

It seemed that this person needed only the space to describe the experience and have its challenges acknowledged. It became clear that whilst therapy and reassurance may be the objective of the therapist, the listening and acknowledging may be of equal or more importance to the individual. Moreover, the intervention or transaction provided by the professional may be more therapeutic for the clinician rather than the individual.

During the interview process I realised the importance of being able to be uncomfortable enough to not offer anything. To be with a person honestly and simply hear them is hard. It is difficult to hear that people are frightened and broken and feel anxious. The human wants to alleviate these emotions, and the clinician version of oneself offers a legitimate framework in which this may happen. However, the skill of 'being with' is of great importance to craft. It was difficult to come to

terms with the fact that we get things wrong as clinicians and that sometimes we are not able to make it better for people.

This experience has changed the way I provide interventions. I aim to allow, and constantly reflect on how I provide, space to hear people in the first instance, whilst simply listening to what their experience has been. I then spend time asking what their objectives may be in light of their time in hospital thus far, and ask them how they've been coping already. With this discussion we can describe ways we could co-create their therapeutic intervention. This approach to providing a swallow therapy intervention may be effective and empowering as the individual may be more able to be engaged, feel valued and take ownership of their recovery at a time when they feel less than human.

It seems possible that to provide an effective intervention we need to be deliberate, reflective, critical and self-correcting, and recognise that discussions form more than information giving or professional reassurance. Rather if we provide time and space with an individual, this may form a vehicle for people to feel valued and human at a most challenging point in life. In the end I learned that listening and holding a person's story is giving them something much more than blocking their account by offering 'reassurance'.

Conclusion

These findings provide insight into the complex, traumatic and life altering effects of head and neck cancer surgery. People experienced a range of symptoms, along with a range of reactions and responses to these symptoms, which involved both physical and existential challenges. The first overarching theme 'I never dreamt' covered the individual's experience of their preparation, surgery, coping and recovery. People described their lack of recognition around what life may be like after surgery along with the reality of managing their altered cosmetic appearance and ability to communicate, potentially for the rest of their lives. A person's search for strength and reflection on their journey through diagnosis to discharge from hospital provided some insight into the way people may manage and feel as a result of these experiences. These findings were important as they made clear that the terms 'coping' and 'recovery' were person specific and movable, and they were not limited to biological or easy to measure components of life and living.

The analysis went on to expose the relational elements of care between the participant and the clinical team, where language and discussion formed more than information giving in the second main theme 'They look at you and they speak to you'. Communication became a vehicle for people to feel valued when they felt less than human. People described the importance of time, and the

feeling of being given time by a professional. This also engendered a sense of being enabled to feel like a human being.

The communication transactions, along with the opportunity to function and be recognised as a human being formed fundamental strands of a person's recovery from surgery. A component of this transaction was identified in the issues people experienced in losing and regaining control. People could describe how it felt to have no choice and the sense of futility and frustration this resulted in. Conversely a small number of people also explained that they felt they had trusted their life into the hands of a health care professional and needed to believe that they would get better.

The personal reflection considers the challenge and tensions which may exist when receiving and hearing the experience of someone who undergoes head and neck cancer surgery. The reflection identifies the human attempt to placate feelings of sadness and anxiety with reassurance, and contemplates to whom this reassurance is of greater benefit. The reflection describes the value of being deliberate, reflective, critical and self-correcting as a clinician, and the importance of recognising that discussions offer more than information giving. These concepts will be described in detail in the following discussion chapter.

Chapter 5 Discussion

Introduction

This chapter discusses the findings of the research and considers their potential application to clinical interventions and service delivery. This study aimed to explore people's experiences of their swallow therapy following surgical treatment of head and neck cancer. To meet the aim of the study, the following objectives were identified: to explore the experiences of people with swallowing difficulties following surgical treatment of head and neck cancer, to explore how well prepared people were for the effects of surgery on their swallow competence, to explore the experience of receiving dysphagia therapy from a speech and language therapist, to understand the components of effective or non-effective therapy from a patient's perspective, to inform the development of optimal swallow therapy interventions and to develop a therapeutic intervention model for people who have dysphagia following surgical treatment of head and neck cancer.

This chapter explores the key findings from the research and offers reflections and insights regarding what a swallow therapy intervention may need to include and considers ways clinical practice could be developed to meet the diverse needs of people with head and neck cancer. The strengths and weaknesses of the study are also discussed.

Key findings

The post-surgical phase was complex and challenging for people with head and neck cancer. For many this particularly traumatic time was compounded by the individual's lack of ability to communicate and discuss their experiences easily. The themes which emerged from the data were broadly categorised into the individual's experience of the physical and emotional impact of the surgery, the clinical communication, and the relationships which formed after surgery.

There were two overarching key findings from this study. The first, represented by the finding 'I never dreamt', was that people found head and neck cancer surgery more challenging than they had imagined. The surgery changed the individual who existed before the operation to a new and altered version of themselves, which did not look or function in the same manner. There was no way they could be fully prepared for how hard this would be, or how it would impact on an array of different aspects of life. The second key finding, described by the theme 'They look at you and they speak to you', involved the relationship with the health professionals at the time of surgery. Health professionals were able to look past the surgery and connect with the person. In this way they were able to be with the individual and provide a safe space for recovery to begin and to acknowledge the individual's humanity at a time when they felt this was challenged.

I never dreamt

The first overarching theme identified how people felt that there was no way that they could be adequately prepared for the enormity of what would happen to them. They valued the preparation they were given, but this was largely about physical changes and potential symptoms. They were less prepared for the challenges to sense of self and personhood that they faced. For health professionals working with this group, questions arise about whether there is more that could be done to prepare people. For example, should attention be paid to preparation for the more existential changes that they face and, if so, how might this be done? It may be that this could be delivered by a person who had previously undergone a similar surgery rather than the professional groups who currently provide this intervention. This could enable the individuals to exchange information beyond the physical changes and symptoms and explore the more human aspects of change and transition.

It is important to consider whether the presumed relationship between optimal preparation and reduction in physical or emotional symptom burden exists, and if it does whether it is a causal relationship. A recent systematic review by Waller et al. (2015) explored the impact of preparatory education for people with cancer on patient outcomes and health care utilisation. Patient satisfaction, psychological wellbeing, pain, length of stay and anxiety were used as measures of outcome of the preparation. There were minimal reported benefits of the pre-operative education, potentially due to limitations of the outcome measures used to determine impact (Waller et al. 2015). It is also possible that the structure, content and delivery of the education were not informed by patient input and guidance, which may have limited the potential benefits. A further limitation was the quantitative tools used to collect information on the impact of the intervention. These are unlikely ever to be sensitive enough to collect data on how the preparation impacted on experiential components of care, as the findings from this research study identified the diverse and individual effects of cancer and its treatment. Participants explained that words could never prepare them for what was for some an existential transition, and loss of sense of self. In the context of the findings from Waller et al. (2015) it seems pertinent to explore not only whether a relationship between preparation and a reduction in post-operative symptom burden exists, but also how the realities of symptom burden may be developed and included within qualitative measures of outcome, to reflect what individuals believe to be important. It is unlikely that quantitative tools would be appropriate or able to support the development of this field as sensitively as qualitative approaches.

If it remains impossible to help people accurately anticipate the difficulties they face, health care professionals need to be aware that people will continue to feel unprepared for challenges post-surgery and to allow them space and time to express how hard this process is for them.

Like this for the rest of my life

This sub theme considered the changes participants experienced, alterations to their sense of self, sense of ownership of their bodies and their ability to choose how they spoke, ate, or looked when they spoke. The findings resonated with concepts raised by Levi-Strauss et al. (1969) regarding the meaning of food in a social context, specifically choice making and the denoting of social status. People were unable to choose specific foods they wanted to eat and their diets were limited to particular consistencies, as they needed to adapt their approach to eating and drinking to avoid choking. Alongside this, some of the social compromises that people faced included losing their job, being embarrassed about the way they looked, dribbling, and being unable to say the names of their children. They were unable to partake, discuss and manage their altered selves in public easily, and some people therefore avoided being in public environments. This finding reflects work by Frank (1995) and his description of the way people with cancer may lose their sense of self and the space to have their experiences heard. Frank (1995) explored individuals' sense of self and relationship to their bodies. He described the monadic body which is that of the individual alone, the sole person who experiences their cancer, separate to others. Conversely, the dyadic body also has an individual experience, but recognises others who may share their reality. Frank (1995) explains that there are fluctuations on the continuum of how a person associates with their body, and that an element of choice exists regarding whether a person lives as a monadic or dyadic body. People in this research study may not have had a viable choice to be their dyadic self who could share their experiences with others in a similar position, as their means of connecting to others through communication eating and drinking had been lost, potentially for ever.

It may be of benefit for health care professionals to provide space for a person to be their monadic self and to describe how this feels, which may include the fear of being altered for ever and different to their friends and family. However, the provision of clinical interventions which could support the individual to move beyond this monadic self are also likely to be of importance. For example speech and swallow therapy may enable individuals to communicate and engage in human rituals such as eating and drinking and talking which allow them to connect with others as their dyadic self, to help support them to manage the lifelong changes head and neck surgery may cause. It could also be of benefit to develop a psychological intervention which supports the person to recreate themselves as a dyadic self.

You just do it

Individuals searched for and utilised their own inner strength to support their capacity to manage the post-surgical phase. Some informants described their search for strength which related to their sense of responsibility or their personal relationships. Not all informants reported this inner strength

and ability. It is interesting to note that this was not reported to be explored or facilitated by the healthcare professional. However it seems possible that an individual could benefit from the support of the clinician to encourage and enable them to acknowledge this capability to search for strength. How this may be achieved practically is complex and would require specific skills. Many issues which have been detailed below may influence why this is not currently provided.

In the first instance it is pertinent to consider whether health care professionals recognise the potential of the individual to call on their own strength and capacity to cope with surgery. As this skill and ability has not been identified previously in literature regarding therapy in the post-surgical phase, it may be unsurprising that this is not regularly described or deliberately discussed in clinical interventions. It is also possible that health care professionals do not attempt to seek out the individual's capability to call on their own strength during a time of trauma and challenge following surgery. This may be due to the perceived burden this could cause to the individual, at a time when they require looking after rather than being asked to find their own strength. As described in the personal reflection it may be habitual for health care professionals to provide a physical intervention, rather than support an individual either to be with their challenges or to perhaps generate their own coping strategies.

The findings suggest that the health care professional could consider a number of ways to help individuals identify appropriate self-management strategies. Barlow et al. (2002) suggest these may include goal setting, carer support, counselling and group support. This dialogue may serve to help the individual identify their own strategies to self-manage, and could provide the health care professional with valuable information about what the individual may need support with. It may also help to identify the individuals who do not have the ability to search for strength.

A study by Krebber et al. (2017) exploring a person's motivation to target psychological distress amongst people with head and neck and lung cancer, identified a range of perceptions regarding why people may engage with a self-help programme and the outcomes. People engaged with the self-help intervention for intrinsic or extrinsic reasons, either for their own perceived benefit or for the benefit of those around them such as the healthcare professional. This resonates with the findings from this study where people described having a responsibility to others. Krebber et al. (2017) showed that some people found a self-help programme alleviated psychological distress and had positive psychological changes whereas others reported either no psychological changes or increased psychological distress. These findings reiterate that people are individual, so a single approach to addressing motivation and self-help is unlikely to be effective. Instead an individual's experience could guide and dictate the development of interventions to support people to self-help

and manage symptoms, especially at a time when they may be vulnerable and transitioning post-surgery. To encourage and enable those people who can self-help and manage to do so with person centred interventions, and identify those who cannot so that they can be supported optimally is of great importance. There is likely to be a fine line between 'caring for', 'doing to' and 'encouraging self-reliance', which requires careful navigation from the health care professional.

It's a journey

People experienced a transition after surgery, no longer the person they were, but not yet recovered to the person they would be. As this research didn't explore the time beyond discharge from hospital, it wasn't possible to consider whether the liminal phase continued beyond discharge and recovery at home, although this seems likely. It was apparent that the liminal space people experienced during their stay in hospital was a safe space where they could begin the process of adjusting to the changes that were happening to them before they had to go back to being in the world again. This transitional phase happened on the ward whilst they were recovering from their surgery, receiving rehabilitation, and awaiting discharge home. Participants were no longer physically the people they had been prior to surgery, who were in control of their bodies, and were not yet able to easily control their new selves. This was obvious in the challenges people experienced, predominantly with eating, drinking and speaking.

The identification of this liminal phase for people who have received surgical treatment for head and neck cancer is a new concept and requires further exploration to understand whether it applies to and influences an individual's needs at other phases from diagnosis to treatment. It is likely that the acute post-surgical time may represent the 'betwixt and between' described by Turner (1987). With this in mind, the clinical team should be aware of the impact of this issue, and attempt to provide interventions which recognise and allow space for this experience.

It seems possible that the individual's successful "re-entry" (Scott 2014) into a meaningful social and cultural role could be reliant on careful navigation through this liminal state. As rehabilitation post-surgery may be a central part of physical recovery, it is imperative that it includes and attends to these complex wider contexts. People are likely to require more than improvement in speech or swallow function alone. They may require recognition of the journey they have undergone, acknowledgement of the person who has been lost following surgery, and support to re-enter their lives in a way they deem adequate, sufficient and meaningful. To do this the professional would need first to recognise the existence of these wider issues, give space for the individual to explore them and be prepared to allow the individual to describe what may help them achieve this new and meaningful life. The nature of a rehabilitative intervention to improve a function that is lost or

damaged, during a time when a person is also experiencing an existential transition, requires careful planning and administration. The loss and change experienced was not limited to physical ability, therefore rehabilitation should not solely address the physical issues. This concept fits with the report of the individuals needing to connect with the health care professional and experience space and support within the interventions they received.

The importance of reducing bed stay in hospital and the associated costs is well documented (Alderwick et al. 2015), and discussed frequently in the media. However, the findings from this study identify the value of time spent on the specialist head and neck cancer ward after surgery.

Informants identified being made to feel safe within the confines of the ward, and with the support of the professionals. Beyond this, it was clear that people could note and describe the importance of being with staff who could help them cope with their altered selves.

The time on the ward after surgery should not be dismissed as simply a physical necessity. The findings demonstrate that the staff have the capability to create a physical and metaphorical space within the ward in which people are able to experience liminality, changes to the way they could speak and swallow and overwhelming emotions regarding loss, anxiety, change and recovery. This environment itself may be healing and therapeutic to be within, which should be considered and recognised, as bed stay days are seldom described in terms related to benefit to individuals. Whilst it is not suggested that there should be extra time spent in hospital when resources are limited, it is important that the true value and potentially invisible support provided by being within an institution is recognised.

The recognition of this liminal state after surgery suggests that the content of an intervention may need to include discussing transition, change and being on the threshold of a new physical and social sense of self. This may support the individual to experience these phenomena within a safe and supportive framework, whilst being enabled to communicate, swallow and function in the best ways possible. In practical terms, this could involve discussing how the individual may manage meal times at home, how they feel about going outside or to public environments and providing strategies to manage concerns about public eating and speaking. The importance of the hospital environment in which people receive care should be recognised and efforts should be spent protecting its rehabilitative value. It seems likely that offering therapeutic intervention outside of the hospital as an outpatient, to support this potentially ongoing journey is also appropriate.

They look at you and they speak to you

The communicative skill of the clinical team was fundamentally important and had a significant impact on the individual. The findings demonstrated the importance of the individual feeling that

the clinician had looked at them as a person, and communicated with them, without simply seeing their altered face. This was particularly important when the participant had no voice with which to communicate. To be looked at and spoken to seemed to help the person feel like an individual with an identity, even if they didn't have a voice. At a time when people felt they had lost themselves and essential elements of their personhood, being looked at and spoken to was of great value.

Part of being spoken to in an effective way was the clinicians ability to make the individual feel that the team gave them time and space for this altered and specific type of communication. In reality, it is well recognised that clinicians have limited time and are under significant pressures. However, these data demonstrated that despite this, the clinicians were able to make people feel that they could provide time and space. This expertise is important as the perception and belief that the clinical team were providing the individual with time and space seemed to allow the person to exist somewhere and feel valid when they may have been in a state of displacement.

To be looked at and spoken to represented a quality component of care from the perspective of the individual, it was of great value to them personally and supported their recovery. It is interesting to consider whether the health care professional would have recognised this in similar terms, and how the clinician was able to achieve this approach to care. Farr and Cressey (2015) explain that professional standards, values, motivations and tacit knowledge influence how care is provided, and the quality of this care. It is therefore important that the findings from this study are fed back to clinicians, through education and clinical guidelines, to inform and develop their understanding about how their relational interventions have a positive impact on people with head and neck cancer.

You've got to be able to connect

Informants described the importance of connecting with the clinical team. They reported the effects of this connection which made them feel safe and cared for while at the same time not de-skilling the individual or encouraging a sense of dependence on the clinical team. These two issues may be in tension at times and therefore should be recognised and attended to, such as providing information on ways the individual may self-care to enhance their independence, and co-creating aims and objectives during the post-surgical phase.

The findings identified the potential challenge in providing clinical interventions to nurture and support individuals, whilst enabling them to feel independent and able to manage their compromise in the long term. Inevitably people's emotions fluctuate, influenced by context and external stimulus. However, at points where people feel able to engage in self-care, or try to control and manage their immediate environment in hospital, it seems important that this should be facilitated.

Epstein and Gramling (2013) describe ways clinicians may promote engagement with patients to facilitate shared decision making; these include, but are not limited to, developing a shared attentional focus, tailoring information and informing preferences.

There are times post-surgery when individuals may be physically unable to manage their own health needs due in part to the physical limitations caused by the surgery. At these points the wider team will be facilitating the majority of care. However, as the individual's capabilities improve in line with the usual recovery trajectory, it is important that the clinical team also supports the person to self-care. It may be tempting to nurture and support the person totally whilst they are compromised after surgery, especially if there are individuals who feel they want to abdicate responsibility to the health care professional to feel totally cared for. However, it is important that the nature of the care provision is balanced alongside the individual's recovery, so that within a supported environment the person who has undergone surgery can begin to feel confident and able to manage some of their post-surgical symptoms with a degree of independence.

It is possible that health care professionals themselves could achieve personal reward from adopting a maternal caring role, where feedback from a person with head and neck cancer could reinforce this relationship. For example if a clinician felt that they were supporting a vulnerable person to improve physically by carrying out specific tasks, they may continue this support to reaffirm their own sense of feeling needed and of value rather than teaching the individual to self-care. This maternal approach could yield mutually rewarding and positive outcomes in the early phases of treatment, where the person feels safe and protected by the health care professional, and the professional believes they are providing personalised nurturing and effective interventions. The tension and balance of attending to the holistic needs of the individual to create a safe space on the ward, and providing maternal care is important to recognise.

The term 'maternal' has been deliberately used in place of more traditional reference to 'paternalism'. Specker Sullivan (2016) offer a definition of paternalism; acting in the best interests of an autonomous person, without their expressed will, or deliberately acting against their will. Conversely, maternalism is based on the concept that where a relationship exists, one may discern the will of another, and act in their best interest (Specker Sullivan 2016). There is no suggestion that health care professionals disregard the will of the individual, rather there is a risk that they may habitually assume and act in what they believe to be the individuals best interest.

Epstein and Gramling (2013) describe the risk of clinicians believing they are acting in the best interests of the patient, when in fact the voice of the patient has been silenced and the clinician

deceives themselves. This is a substantial risk for clinicians supporting people with head and neck cancer. Firstly their voices may be physically silent so the clinician may be incorrectly interpreting their perceived needs rather than their actual needs which may be complex, emotionally fraught and difficult to explain. Secondly the potential benefit the clinician may achieve by providing the nurturing, maternal and personally rewarding care described previously may reduce the clinician's ability to attend to problems which they may not be able to solve, such as being with the individual rather than doing things for them.

Navigating and developing the relationship between health care professional and individual in a balanced and healthy way is undoubtedly difficult, and has not yet been explored in this clinical area. Optimal negotiation of this relationship could include detailed discussion about which components of care could be carried out by the clinician or the individual, and how these may change and develop during their time in hospital. It may also be possible to identify collaborative aims and objectives regarding recovery and function so the individual feels engaged and begins to re-establish their sense of autonomy and choice making at a time when they feel voiceless. This could help avoid the potential development of maternalism in the post-operative phase.

I felt like a human being

A positive component of the relationship which formed between the health care professional and the individual seemed to develop in part from the capacity of the professional to recognise the effects of surgery without having a personal reaction to them. The health care professional seemed able to medicalise the problems people had, whilst still being able to see the individual who existed alongside these symptoms without judgement or personal cost. It seemed difficult for the person to achieve this in the same way with their friends and family. The restoration of a person's sense of identity seemed to be facilitated in part, by the relationship with the health care professional.

Chochinov et al. (2015) explore and describe the value of recognising personhood, which enables patients to feel like a person, and subsequently results in them feeling satisfaction with their care. This seems to be reflected in the way participants felt following interactions with the team. The findings also resonate with information described earlier in the thesis by Sen (2008) which considered how people may reach a valuable state of being. The social interaction the participants experienced with the clinical team seemed to substantiate this sense of being, when people were able to exist beyond the changes to their face which had the potential to define them. This information should be made explicit to health care professionals through educative opportunities, so they are able not only to recognise the significant effects of subtle interactions and their communication style, but moreover practise their ability to support an individual in this way

deliberately to improve clinical outcomes. This would require the health care professional to recognise their skills advance beyond that defined by their job title, for example surgery or speech therapy, and involve these fundamental relational components of care.

Give me your life into my hands and I'll look after you

The staff created a safe environment on the ward where the individual felt looked after whilst experiencing a transition. This was an individual experience where some people seemed to want to devolve responsibility to the health care professional, whilst others developed more balanced relationships. As so many social, emotional and physical components of life are changed by this surgery, health care professionals may be at risk of becoming all things to all people during the acute phase, without the resource or capability to maintain this relationship.

As people seemed to equate recovery and quality time spent with the professional with positive outcomes, it is important to consider how clinicians managed to facilitate this feeling. Hochschild (1983) describes emotional labour as 'This labor requires one to induce or suppress feeling in order to sustain the outward countenance that produces the proper state of mind in others-in this case, the sense of being cared for in a convivial and safe place.' (page 7). It is possible that the clinicians were practising emotional labour in the time spent with people who had surgery, prioritising the time as clinically valuable and explaining what was being provided to the individual. This may in turn help create the feeling of deliberate space and time in spite of other clinical pressures, and raise awareness of the value of clinical interventions which cannot be measured simply in quantitative or functional terms. The provision of this type of care is likely to be emotionally costly for the clinical team, therefore supportive structures may need to be established to enable and support this.

There is evidence within seminal literature that nurses who feel supported and cared for go on to provide sensitive care (Smith 1992). In order that clinicians can be deliberate about the content of their interventions to include and identify what the individual requires from them, and to be flexible when these needs change, it seems important that they also feel cared for and supported. This could be achieved in numerous ways including, but not limited to, creating supervision structures and multi-disciplinary educative opportunities. In some institutions this may already exist, however given the variability in clinical practice in head and neck cancer dysphagia management across the UK (Roe et al. 2012), it is possible that these infrastructures may not be consistently available.

You'll find another way

The nature of the rehabilitation provided by the SLT was a valuable finding of the study, as this intervention at this particular time post-surgery is poorly understood. The information about how participants perceived the SLT was in contrast to findings of other research studies such as Ullrich et

al. (2010) who found that an SLT may not be equipped to manage the psychosocial needs of people with head and neck cancer. This finding may reflect clinical practice which focuses on functional dysphagia outcomes, such as 'boot camp' concepts to improve swallow function alone (Hutcheson et al. 2013). However, people in this study described the skill and ability of the SLT to understand them, educate and create iterative interventions, such as increasing the complexity of the therapy provided day by day, explaining the anatomy and physiology of swallow, and discussing the emotional elements of the individual's experience. The value attributed to time spent with the SLT and her understanding of the participants provided more than physical rehabilitation. This was similar to the Ellis-Hill et al. (2008) life thread model findings which explain the importance of being with a person therapeutically. This information raises questions about whether the complexity and fundamental constituent parts of rehabilitation interventions are well understood. 'Being with' a person is infrequently discussed in rehabilitation research, where the dominant paradigm is about measurement of functional improvement. This study suggests that the therapeutic intervention moved beyond functional gain, and included relational components of care which were healing and of benefit to individuals.

The findings suggest that dysphagia impacts on all elements of life (Patterson et al. 2013). It exists in the messy and complex landscape of the post-surgical phase which includes lack of sleep, intrusive medical interventions and feeling overwhelmed. Whilst it may be tempting to reduce dysphagia therapy to a specific symptom, requiring a specific intervention, by a specific individual, to improve swallow competence, in fact, dysphagia may exist alongside many different symptoms, requiring numerous physical, emotional and psychosocial interventions, delivered by more people than just the SLT. It is important to recognise that dysphagia therapy was provided by many influential actors and agents including the SLT, consultant, nurse, and family.

The delivery of the intervention is of importance, so that the mode and methods meet the physical, biological and emotional needs of the individual. Optimal delivery seems to include the provision of quality time and space, recognition of and the opportunity to discuss issues other than swallowing, discussion about physical alterations, and confidence in the SLT to have a high level of understanding and skill to manage the complexities of swallow compromise. The combination of these attributes and approaches seemed to enable people to feel they had received personalised care, and supported them to be restored to a meaningful human existence.

The organisational components of delivering rehabilitation are important to consider and describe, as there is an increasing pressure to deliver cost effective sustainable care in a challenging financial environment within the NHS. Providers and commissioners require the workforce to work in a more

efficient way, and healthcare professionals are under constant scrutiny to demonstrate the effectiveness of their interventions in health related outcomes. This tension can be difficult to manage and it is of note that the recommendations from this study suggest developments and adaptations from standard care, to develop the culture and understanding about what people with head and neck cancer need. It is of importance that this information is recognised and valued by health care providers, to ensure quality care is available to individuals and that outcomes are not simply target or finance driven (Francis 2013).

In terms of efficiency savings, early rehabilitation programmes are being developed in liver and colorectal surgery to meet the service delivery requirement to reduce length of stay in hospital (Melloul et al. 2016). These interventions have not yet been shown to yield functional or service management benefit such as reduction in bed stay days for people who have undergone head and neck surgery. Indeed, people who undergo head and neck cancer surgery may develop complex individual post-operative complications and have prolonged length of stay (Dawson et al. 2017). With this in mind it seems fundamental to explore diverse ways services may be most efficiently delivered and to consider the quality and more subtle components of care. The suggestions made from the findings of this research involve these relational facets which have the potential to develop the culture and understanding of what individuals need after head and neck cancer surgery beyond wound healing. The changes in clinical interventions suggested are unlikely to be either financially costly or involve increased bed stay days for example. However they provide an alternative perspective on post-surgical care, with a focus on emotional and psychosocial support that would require some development of clinical skills and education.

Implications for practice

The original aim of this study was to develop a model for practice for speech and language therapy interventions for people who have had head and neck cancer surgery. While there was not time in the study to develop and test this model completely, some suggestions and implications for practice can be made for further exploration. The two key themes that arose from this study 'I never dreamt' and 'they look at you and they speak to you' encapsulate on the one hand the extent of the difficult physical and emotional challenges faced by the individual, and on the other hand the responses of the health professionals who supported the individual through this challenging time. It is suggested that a model of care could be built on these two themes that run through the whole of the cancer journey. The basis for the development and consideration of a future conceptual model has been developed below.



Implications for practice on the theme 'I never dreamt' include considerations of how people can best be prepared for what is to happen to them, how to help them adjust to the physical alterations they experience and how to support them in the transition from the person they were before their surgery to the person they will become afterwards. Implications for practice on the theme 'they look at you and they speak to you' include finding ways to connect and enabling people to feel human. These themes help us to understand that a therapeutic relationship can be therapy in and of itself. The provision of specific techniques and training of new skills is only one part of the therapeutic intervention.

The findings introduced concepts about people's experiences post-surgery which have implications for clinical education, training, supervision, networking, and developing clinical guidelines. The findings also suggest a requirement for the refocus of clinical measures of outcome, beyond surgical

healing and the absence of disease. This research is timely as Alderwick et al. (2015) describe the importance of developing clinical practice with patients, to improve care and reduce costs within the NHS. The challenge of delivering an estimated £22 billion of productivity improvements by 2020/21 (Alderwick et al. 2015) highlights the lack of capacity for the health service to spend more. However, there is an opportunity to change clinical practice, with the potential to reduce symptom burden and therefore an individual's reliance on the NHS. In the case of head and neck cancer surgery, this would require a departure from current care. Alderwick et al. (2015) explain that "Improvement takes time, and progress is typically made through a line of small jumps rather than one giant leap." (page 6). To develop practice there needs to be a shift in beliefs about what is required for people post head and neck cancer surgery. This may be challenging within the context of a financially limited NHS, however it could be considered a 'small jump' towards improving outcomes.

There is an inherent tension throughout these findings, between the proposed requirements for an individual's physical, emotional, social and cultural recovery and the expectations of an acute service provider. Some of the implications for practice suggest allowing a person time and space, acknowledging their challenge and experience through a liminal phase of their life, and helping them to navigate social networks outside of the hospital. Within the context of cost savings within the NHS this may not be considered a priority. The medical model and perhaps a positivist approach to head and neck cancer surgery may purport the responsibilities of the NHS and service provider to be complete once the patient's wounds were healed and they were able to return home safely. In this instance the suggested implications for practice could be considered best placed with agencies outside of acute care. However, the findings contradict this position. The chasm between psychosocial and physical symptoms is artificial, and only fits within a positivist medical model. This interpretivist methodology has demonstrated their co-existence and impact on one another.

In order to provide care that meets the holistic and complex needs of the individual following head and neck cancer, there needs to be a departure from the belief that surgery simply removes a tumour from a patient with cancer. Instead an intersectional approach which recognises the many components of an individual and the changes to their identity and sense of self after surgery may be more realistic and healing. This would take time, skill, and engagement from clinical teams. Intersectionality covers the multiple categorisation of an individual; in feminist research this tends to include race, gender and sexual orientation. Within feminist methodologies intersectionality is concerned with issues associated with reducing a person to just one category, overlooking the relational element of social and cultural roles (Lykke 2010). It seems possible that intersectionality may be appropriately translated to the post-surgical phase where people are simultaneously a

patient, a parent, a member of society with a job, and an altered version of their physical-self following surgery. This feminist position on intersectionality provides a perspective in which a person is not reduced to 'a patient', and instead recognised with their plural identities. The adoption of this concept may limit the potential for a patient's voice to be silenced by a professional (Epstein & Gramling 2013), by enabling the individual and their concurrent and multiple emotional and physical needs to be heard and attended to. If clinical teams considered and recognised the intersectional components of an individual, a more comprehensive and holistic recovery after the acute phase could be achieved. The practical ways in which clinical care could develop to meet the holistic needs of people who have undergone head and neck cancer surgery are detailed below.

I never dreamt

People reported that whilst they could be prepared for the physical components of the surgery, the emotional and psychosocial effects were more challenging even to consider. Health care professionals should explore whether it is possible to prepare people in more holistic terms for the effects of their surgery. This would involve creating and testing interventions which target and attempt to support these specific experiential and existential issues. This could involve inviting people who have already undergone a similar surgery to the pre-treatment session, to provide one to one insight into the lived experience. It would also be possible to create patient videos with information from people who had undergone surgery, and or written information from studies of this kind. These methods could include information on the emotional and psychosocial effects of the surgery, and could be tested for effect in future research. Multiple modes of information giving would also enable the individual and their family or carer to choose how they would like to receive information which may encourage them to feel an active participant in their care from the outset. This approach would also ensure clinicians were using their clinical time in the most effective way.

The preparation phase may also be optimised if time is spent orientating the individual to their own coping strategies and inherent strength, which may help them manage the potentially life altering effects of head and neck cancer surgery. This strength may exist and have been utilised in other areas of their life, as a result of previous experiences. Some people may not be able to identify, describe or use these individual skills so targeted input from the multi-disciplinary team would be required. This may involve exploring how the individual would like to be supported, for example the use of online forums, blogs, visits from the clinical nurse specialist or head and neck counsellor, and or spiritual support. Identification of optimal means of support would require deliberate questioning and collaboration between the clinician and person with head and neck cancer. This could be achieved by using and developing technology like the Patient Concerns Inventory by Rogers et al. (2009). The use of this device has demonstrated how a touch screen computer can enable a person

with head and neck cancer to identify their priorities before a consultation, and to detail which member of the team they would like to see. This technology has been shown improve the quality and specificity of clinical consultations, without significantly prolonging the duration of time the person was in their appointment (Rogers et al. 2009).

It may also be pertinent to consider ways social networks may be utilised to support individuals. Engagement with spouses, carers, patient groups and online forums could be explored in order that the psychosocial components of the effects of head and neck cancer surgery may be addressed within and beyond the confines of the hospital environment. The effects of head and neck cancer were not simply a clinical medical issue, so the support people are offered needs to consider how it may involve engagement with teams away from the clinical setting. Macmillan cancer support forums (<http://www.macmillan.org.uk/information-and-support/coping/getting-support/talking-to-us>) and patient groups run by head and neck cancer specific charities (<http://getahead.org.uk/get-head-patient-group-meeting/>) are available; however it is unclear to what extent these are currently being utilised. Developing clinical practice could involve more deliberate liaison between clinical teams and local charities, to create networks and support systems for people after surgery. This could extend the clinical pathway beyond the hospital admission and support a person's transition after surgery.

The physical changes people experienced existed at rest, when people observed them, but particularly when they attempted to speak and eat. Health care professionals may support people to manage their physical symptoms by acknowledging and discussing these changes and giving people the space to discuss how it feels to look and speak differently. When individuals are concerned that they would be permanently altered by their surgery, it seems appropriate that information and support to reiterate the recovery and change trajectory would be imparted. However this research shows that just being with the individual, and allowing them the opportunity to discuss their feelings is therapeutic in itself.

Following head and neck cancer surgery people experienced a transition. They were no longer the people they were, but not yet the person they would be. It is likely to be important that professionals recognise this change which may result in people feeling displaced, whilst they lack control over the way they look and manage their altered self. People may benefit from having a discussion about this transition, to recognise that other people have reported feeling altered. It is possible that creating a social group within the ward environment for people who had undergone head and neck surgery could be of value. As the usual facilitators of communication (speaking, eating and drinking) were challenging, this safe environment could provide a forum for people to

share their feelings and experiences with people in a similar situation. This could involve inviting people to either a common dining area or to a communication group on the ward. This new social network could also support people to understand how others were progressing and what they may expect during their recovery.

They look at you and they speak to you

Communication was more than transference of information. It allowed the individual to collaborate with the health care professional and to influence the information provided to them when they had limited ability to communicate easily. It seems important that opportunities to talk with the health care professional on a human level are fostered during the post-surgical recovery on the ward. This supported people to feel human, valuable and of importance, as a person rather than a patient, and therefore potentially helping their emotional as well as physical recovery. Whilst this interaction may have been subtle to the health professional, it was of great importance to the individual. Time during daily ward rounds and observing interdisciplinary working seemed to reassure people that the team was working together and wanted them to recover. Therefore it may be useful for the team to recognise the benefit of daily ward rounds to the individual. This time was not just of benefit for clinical team and their information gathering. The ward round interaction provides an opportunity to present and demonstrate the collaborative and person centred care the team can provide to the individual on a frequent and daily basis, whilst offering the individual the chance to influence their care plans.

The team providing health care interventions may benefit from being mindful to avoid the development of a maternal role with people who have undergone head and neck cancer surgery. For example, time may be effectively spent defining what components of care the professional and the individual may carry out rather than the clinician assuming all responsibility. This would reduce the potential for a dependant relationship to develop, where the professional could unknowingly derive benefit from providing seemingly supportive interventions. It seems important that enabling the individual to feel able to acknowledge and manage their altered self is central to the provision of care post operatively. This may not be standard practice for many clinicians and is therefore a development of current NHS care.

‘Being with’ the individual was as important as providing an intervention. The personal reflection noted that the clinician may find this challenging to achieve and emotionally labour intensive. A grounded theory study by Caty et al. (2016) also recognised that SLTs working with people with head and neck cancer experience challenging clinical situations where there are no obvious protocols or guidelines to rely on to support reflective practice. Caty et al. (2016) proposed a framework to

structure clinical reflections. A component of this (2016) included 'Being in the moment' with a patient. This mirrored the findings from this research study which identified the importance of allowing space and time to enable the individual to feel human. The practicality of achieving consistent and high quality reflective practice remains a complex issue within health care. Harding et al. (2014) suggest that barriers to employing evidence based practice within groups of Allied Health Professionals include a lack of perceived value, prioritisation of patient flow and limited resources (Harding et al., 2014). With this in mind, a multifaceted approach to raising awareness of the value of reflective evidence based practice is required. This could involve reviewing teaching at an undergraduate level to educate clinicians on the value of reflection and its potential to improve patient-clinician interactions. It is also important to develop the evidence base to explore how these concepts may be optimally embedded into clinical care. It would be possible to develop questions clinicians could ask themselves, to structure their self-reflections. These could be derived from the findings of this research, and would mean the clinician was considering the needs of the individual not just physical components of care giving. These could include:

- How did I give space for, and hear the individual's voice?
- Did I spend adequate time with the individual, how did I know it was adequate?
- What tells me the clinical skill I used was sufficient and of good quality?
- How did I support the individual to manage their emotional and physical symptoms?
- How did I help restore this person's sense of self?

This list is not exhaustive, however it may begin to encourage clinicians to ask pertinent questions, based on parameters the participants deemed to be important. These types of questions may also help clinicians understand how and why interventions aren't well received by individuals, or whether any relational components of care may impact on why people may not adhere or engage with clinical recommendations.

Strengths and weaknesses of the study

Philosophical position

A strength of this study was its philosophical position. In an area of clinical research where a positivist paradigm dominates, the value of this interpretivist investigation can be demonstrated. The voice and experiences of the individual as well as the information generated on what a swallow therapy intervention may involve is new and an important addition to this area of research. For example, the skills of the SLTs were noted to go beyond providing physical rehabilitation. The SLT

was able to create iterative, person centred holistic care which enabled the individual to feel confident and able to manage their altered selves more effectively. This would not have been uncovered had the study been positioned within a positivist paradigm. This novel information was generated from the individual and their experiences, rather than proving or disproving concepts about what clinicians believed to be the component parts of an intervention. Similarly the data related to how the clinical team can communicate optimally with an individual and support them after head and neck cancer surgery moves beyond communication skills and provides insights for wider professional groups such as the medical and nursing team.

Methodology

The interpretive phenomenological methodology is both a strength and weakness of the study. In terms of strength, the 1:1 in depth interview design allowed original themes to emerge from the data. However, there were also limitations to this methodological approach. The results demonstrated that the relational elements of care formed a large part of the individual's experience, perceived recovery and rehabilitation which were not clear in the design phase of the study. In retrospect, an ethnographic approach may have captured and exposed these phenomena in a comprehensive way as ethnography facilitates the study of the individual and the cultures in which they exist. For example, it would have been valuable to observe the interactions which occurred between the individual and various members of the clinical team to capture alternative perspectives.

Patient and user involvement

Although user involvement helped shape the interview questions and design, there was limited influence beyond this phase. Greater user involvement regarding validation of the themes would have strengthened the study, as the interpretation of the researcher could have been challenged and developed by people who had experienced head and neck surgery. The transcripts could have been validated independently by the participants rather than by the supervisory team alone. The findings and implications for practice could also have been shared with focus groups of both people and families who have experienced head and neck cancer, and with groups of the multi-disciplinary team. This could have enhanced the interpretation of the findings, however timing and funding precluded this from happening.

Timing

The timing of the interview could also be considered a strength and weakness of this study. It was a strength as it explored the experience of an individual at the acute phase after head and neck cancer surgery whilst they remained on the inpatient ward, which had not been investigated previously. As described, there is no evidence available about people's perception or experience of the post-surgical phase, so it is pertinent to explore what happens and how people feel at this complex time.

The study may have been strengthened if it had included several consecutive points of interview, in several different treatment centres. To enable the individuals to reflect back on, augment and develop their ideas and feelings with the benefit of time may have provided another perspective on the post-surgical phase. Similarly it would have been interesting to explore themes which emerged from other treatment centres as a result of the differences in care and approach to the provision of clinical interventions which exist. Unfortunately, it was not possible to conduct a longitudinal, multi-centre study due to timing and funding limitations. Nevertheless, the findings are an interpretation of the individual's experience at this particular point of their lives, having undergone treatment in the study centre, and thus remain an important addition to the limited evidence base.

Rehabilitation models

The literature review identified specific models and theories which may be used to influence rehabilitation for people who receive surgical treatment for head and neck cancer. Each model had potential benefits, these included the concurrent mapping and description of location of disease and impact on function (WHO 2001), the concept of being with an individual and supporting them to re-establish social, psychological processes and life threads (Ellis-Hill et al. 2008). Goal orientated therapy and solution focused therapy was identified to engage and enable the individual's ownership of their rehabilitation (Gingerich & Eisengart 2000), and the Capabilities approach could help define what may constitute a good life for an individual (Sen 2008). These are important facets of rehabilitation, and have the potential to underpin a therapeutic intervention.

A therapist could use components of these models to help frame and structure a rehabilitation session, for example asking a person to answer questions from the ICF framework to identify how their life has changed following treatment. This information could support the individual and therapist to focus their rehabilitation, and measure change following treatment. The goal orientated therapy could be used as a tool to engage the individual in specific tasks, creating tangible aims and objectives. The life threads model could provide a framework to encourage the therapist to look beyond the physical impact of treatment and to be with the individual. However, alone each model is unlikely to meet the complex needs of an individual in the post-surgical phase of head and neck cancer treatment.

The findings from this research study highlighted fundamental limitations of each of these models for use with this group of people. Participants described concurrent and complex issues, requiring individualised rehabilitation, encompassing more than the available models could offer. From the perspective of goal orientated therapy, some people could identify their individual coping strategies and aims, whilst others were unable to. Instead, time spent with the professional being

acknowledged and spoken to as an altered self was of great therapeutic importance. Similarly, the lack of preparation people experienced for their post-surgical change, and the transition they experienced in this context challenges some concepts raised by Ellis-Hill et al. (2008). Specifically stability and coherence in an individual's life, where linking the past and that which has been, to the unknown future to facilitate the rehabilitation process. People described the importance of clinical relationships to support their sense of self, to feel human. Coherence and stability were not identified in the themes; rather emotional processing and re-establishing the sense of being human were paramount.

The ICF (WHO 2001) framework is also considered to be insufficient as a rehabilitation model for people in the post-surgical phase of treatment for head and neck cancer. The framework provides a comprehensive way of mapping physical compromise and the impact this has on function. However it does not provide insights into how these issues may be managed, nor how the identification of these issues may be of benefit to the individual. There is clear benefit to the clinical team in collecting this data, and using a shared language to describe the effects of disease, however less value can be attributed to its use in terms of the individual and their complex needs in this particular phase of treatment.

The contribution and limitations of these models reiterate the importance of developing the theoretical underpinning of rehabilitation models. Data which is generated from the individual and their experiences ensures both the specific context and needs of the person are central. Until now, data about the post-surgical phase had not been collected so it is unsurprising that the rehabilitation models in their current form are insufficient.

Reflection on aims and objectives

There were many aims and objectives identified at the outset of this project, influenced by the available literature and by the clinical experience of the researcher. The interview process, analysis and interpretation of the findings and discussion achieved the following objectives:

- To explore the experience of people undergoing surgery for treatment of head and neck cancer.
- To explore the experience of people with swallowing difficulties following surgical treatment of head and neck cancer.
- To explore the experience of receiving dysphagia therapy from a speech and language therapist.

- To understand the components of effective or non-effective therapy from a patient's perspective.

The objectives regarding development of a swallow therapy intervention model were largely achieved following the analysis, and are demonstrated in the implications for practice section of the discussion.

- To inform the development of optimal swallow therapy interventions.
- To develop a therapeutic intervention model for people who have dysphagia following surgical treatment of head and neck cancer.

It was more complex to develop a therapeutic intervention model than was predicted when the aims and objectives were created. The data collection and analysis captured the challenging reality of undergoing head and neck cancer surgery, of which having a swallowing problem was one component. It is clear from the analysis that the inability to swallow effectively and the subsequent therapy from the SLT was a fundamental part of people feeling connected to the team and it restored people to a more human existence. However, it was not possible to overlook or under report the magnitude of the whole experience people described. The swallow problems were part of a broader context, which require further investigation to refine the proposed therapeutic model.

The findings from the literature review along with the anthropological and sociological insights into what eating and drinking meant, began to uncover the limitations of attempting to create a single swallow therapy intervention. In conjunction with the findings from the data collection it became clear that defining principles and approaches which may effectively underpin an intervention was a more practical response to the aim of the study. Therefore, the proposed model and implications for practice provide concepts which may serve to frame future therapeutic interventions for people who have undergone head and neck cancer surgery. Further research is required to develop these findings.

The remaining objective, 'to explore how well prepared people are for the effects of surgery on their swallow competence' was more difficult to complete. Firstly, the concept of preparation was challenging as described in the theme 'I never dreamt'. Whilst people seemed to recognise that their swallow competence would be altered after surgery, this symptom did not exist in isolation. Swallowing problems happened alongside speech problems, and psychosocial and emotional changes, and people did not tend to describe their swallow in isolation. Secondly, people explained that they could not be prepared for the post-surgical changes, just that they could be given an

overview of what was to come. Participants recognised and understood that the health care team could not predict their swallow in great detail, so they did not seem to expect detailed preparation for it.

In retrospect, identifying an outcome that included the concept of preparation for people who undergo head and neck cancer surgery was inappropriate, and should have been considered in greater detail before becoming an objective. With the knowledge of the existential and human changes people experience, it seems impossible that people could ever be fully prepared for the individual and personal effects of this treatment, not least those pertaining to swallow. That does not render the meeting with health care professionals before surgery ineffective but the practicality of being able to fully prepare people is probably unrealistic.

Chapter 6 Conclusion

The study uncovered the complex experiences of people who undergo surgical treatment of head and neck cancer, and relationships with the clinical team which supported their recovery. The findings and discussion identified ways interventions may meet the needs of the individual and considered how practice may be developed to improve outcomes.

Core messages

The concept of preparation before surgery needs to be reconsidered by clinical teams. Firstly it is unclear whether a relationship exists between preparation and reduction in post-operative symptom burden; further research is required to explore this. Secondly, it may be more effective before surgery to discuss and explore the existential transition people may experience along with their emotional and social changes. This may be delivered more appropriately or enhanced by someone who has previously undergone surgery. It may also be pertinent to consider adapting technology such as the Patient Concerns Inventory (Rogers et al. 2009), so people can describe what they want from a preparatory consultation. Further research would be required to ask a larger group of people this question and develop appropriate parameters to be included with this type of technology.

The transition people experienced after surgery on the ward appears to represent a safe space where healing can take place and the individual can begin the work of adapting to their new persona before needing to make adjustments to their life once discharged from hospital. Part of the clinician's responsibility seemed to be about being with the individual. Being with a person was therapeutic and this human relationship was of great value. It was not about simply providing therapy or information. Suggestions regarding how this relationship may be evaluated by the clinician have been made, including asking specific questions to enhance self-reflection.

People who have undergone head and neck cancer surgery are likely to have a period of voicelessness. This affects their ability to describe their needs and changes the way in which clinicians need to communicate with them. This relationship can be complex, and clinicians need to be mindful of silencing the individual. It may be complex and time consuming to understand disordered communication, however clinicians can avoid deceiving themselves and incorrectly believing they are providing what the individual needs, by checking in with them and giving them space and time.

Speech and Language Therapists provide more than physical rehabilitation of swallow; this is only one component of their intervention. The research demonstrated that swallowing does not exist simply as a well-defined biological entity. It is inherently linked to physical, social and emotional components of a person's life. The Speech and Language Therapist was able to provide interventions that acknowledged and recognised these issues. The findings suggest that the rehabilitation a Speech and Language Therapist provides supports people to adapt to their post-surgical changes and alteration to sense of self. The Speech and language Therapist was able to educate and provide iterative therapeutic interventions whilst being with the individual and their complex symptoms after surgery. This is a valuable skill and underpins the importance of the inclusion of the Speech and Language Therapist within the head and neck multi-disciplinary team. This detail has not been described in previous research. The methods and design of this study could be replicated in other study centres so that Speech and Language Therapy teams could begin to understand how their interventions impact on people with speech and swallow needs to develop the currently limited evidence base.

Future research needs to focus not only on the requirements of individuals with head and neck cancer, but also on the clinical team supporting these individuals. It is expected that there is notable emotional labour involved with providing personalised treatment interventions to people who have had head and neck cancer surgery. Whilst suggestions have been made regarding ways clinicians may reflect on the quality of these interventions, research is required to understand how teams may be supported and encouraged to provide this care.

In order to develop a comprehensive understanding of whether a person's post-surgical phase of recovery has been supported optimally in rehabilitative and individual terms, measures of outcome need to be developed. These measures would need to move beyond medicalised parameters such as length of stay and swallow recovery, to include concepts such as whether a person has felt valued and whether their individual aims and objectives have been attended to. The potential value of deliberately created social environments such as a dining area within the ward, and the engagement

of social networks and online forums were discussed. There is an opportunity to test and evaluate these components to consider their potential contribution to the acute post-surgical phase.

Future directions

The conceptual model provides a framework within which therapy could be focused, based on two overarching themes derived from this research. This requires development and testing. Firstly this could include carrying out further interviews in multiple centres, so that more empirical data could be gathered to develop the concepts. Whilst it may be that no new themes emerge, it would be important to explore this potential. It would then be possible to develop interventions based on this comprehensive model. Focus groups with Speech and Language Therapists, clinical nurse specialists, nurses, surgeons and patient could help identify ways in which these concepts could be translated and embedded within clinical care. This may involve exploring how clinical discussions could be guided by information on experiential components of care, whether written information for professionals, patients and carers could be developed, and considering whether training sessions with members of the MDT could be facilitated to improve understanding of what people with head and neck cancer require after surgery. The success of these interventions could be assessed through similar structured interviews, and process analysis could guide the development of truly patient centred interventions.

The research identified the challenge people may have in identifying with their dyadic self following surgery. More needs to be done to explore this concept, and perhaps improve a person's ability to recognise and connect with others in similar circumstance. Suggestions regarding the development of open ward based dining areas were made and this has begun to be explored within the study centre. Practicalities regarding where and when this dining could take place have been considered and there has been support from nursing staff and patient groups. Swallow therapy within the study centre has also started to include eating and drinking in a public dining area, outside of the ward, with the SLT. This has been developed to address the social issues people described with looking and feeling different in a public arena. Moving the swallow therapy from the confines of the ward and applying the principles into everyday life seems to support the individual to feel safe and capable within a public environment. This also seems to reduce the individual's sense of anxiety about participating in public interactions following discharge home. This intervention requires development and testing, to establish whether the departure from usual care improves outcomes, and if so how. This would also need to be developed with patient groups and clinicians to evaluate this complex intervention.

Surgical treatment of head and neck cancer changes and alters people in physical, emotional and social spheres of life. It disrupts the way people undertake the most human of tasks: eating, drinking, speaking and presenting their faces to the outside world. The immediate post-operative phase may represent the peak of this acute realisation for the individual and this disruption requires a specific kind of intervention from health care professionals which has been detailed in this thesis. This work is of importance as it provides insights into the ways clinicians may enable a sense of self to be acknowledged and restored and to help create a meaningful life following head and neck cancer surgery.

Appendix A-Participant Information

Participant information

Study Title: What are the experiences of people who have received swallow therapy following surgical treatment of head and neck cancer?

Researcher: Camilla Dawson

Organisation: University of Southampton, Faculty of Health Sciences.

Sponsor: University of Southampton.

You have been provided with this pack as you are eligible to take part in this research, which I am undertaking as part of my studies for a Doctorate in Clinical Practice. Please read the following information or ask me any questions. I am available every Wednesday in the outpatient clinics or you can telephone me on: 0121 371 3483 or email me at Camilla.dawson@nhs.net.

What is the research about?

After people have had surgery for treatment of head and neck cancer they will receive advice and support about swallowing and speaking from a Speech and Language Therapist (SLT). This research will gather information on people's experiences of the support they get on swallowing after they have had surgery on their head and/or neck. Information from the study will help improve and develop swallow therapy services.

Do I have to take part?

Taking part in this research is entirely voluntary. I will describe the study to you and answer any questions you may have. You will have plenty of time to decide whether you would like to take part and you can discuss it with anyone you choose. I will come to see you when you are in the ward and after you have had your surgery. If you decide to take part I will ask you to sign a consent form at this time. You can change your mind about taking part in the study at any time, and you don't have to give a reason to leave the study. Taking part in this study will not change the medical care you receive.

What will happen to me if I take part?

You will be asked to take part in an interview. This interview will take place in a quiet private room on the ward whilst you are an inpatient, and will take around an hour to complete. This interview will take place towards the end of your stay in hospital and I will ask you about your experiences of the swallow therapy you received. You can stop the interview at any time. You don't have to answer anything you don't want to. If you would like a family member to attend with you this can be arranged. The interview will be audio recorded. When the interview has finished the recording will be written out word for word and analysed. The information will only be used for this study, and will be stored securely.

Are there any benefits in my taking part?

It is unlikely that there will be any benefits to you, although some people find it helpful to talk about their experiences. Information from this study aims to improve and develop swallow therapy services for people who have head and neck surgery.

What are the possible harms of taking part?

There are no real harms linked with taking part in an interview. It is possible that you may become upset when talking about your experiences. I will be sensitive to this and will have details on where you can get help if you need it.

Will my taking part be anonymous?

Your name will not be used in this study, instead you will be given a pseudonym so I can identify your information.

I will make sure no clues to your identity will appear in any reports, publications or the Doctorate papers.

Interview data will be kept on a password protected computer and available to the research team only.

Any personal information about you or any notes from the interview will be kept in locked storage for ten years. This is in line with University of Southampton data protection policy.

What happens if I change my mind?

You are able to leave the study at any time you want to. Your legal rights or routine care as a patient will not be affected.

What will happen to the results?

The team who were involved in your care will be provided with an overview of the results of the study but they will not be given any specific feedback on their own performance, nor will they be told who provided information about their work.

The results will be presented in my doctorate papers. The findings will also be presented at conferences and published in research journals. Anonymised quotes from your interviews may be used in these reports.

Who is organising and funding the research?

Get Ahead charitable trust are funding the research (<http://getahead.org.uk/research-support/>). The research sponsor is the University of Southampton.

Who has reviewed the study?

To protect you, all research in the NHS is looked at by a Research Ethics Committee. This study has been reviewed and accepted by xxx Ethics Committee. Please ask if you would like to know more about this.

What happens if something goes wrong or I have a complaint?

If you have a concern or a complaint about this study you should contact Martina Prude, Head of the Governance Office, at the Research Governance Office (Address: University of Southampton, Building 37, Highfield, Southampton, SO17 1BJ ; Tel: 023 8059 5058; Email: rgoinfo@soton.ac.uk). If you remain unhappy and wish to complain formally Martina can provide you with details of the University of Southampton Complaints Procedure.

Where can I find out more?

If you want to know more, please contact me on:-

Camilla.dawson@nhs.net

0121 3713483 (Tuesday to Thursday). If I am not available, please leave a message and I will return your call as soon as possible.

Appendix B- Consent form

Consent Form

Title of project: What are the experiences of people who have received swallow therapy following surgical treatment of head and neck cancer?

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Sponsor: University of Southampton

Please initial in the boxes if you agree:

I understand and have had the reasons and nature of the above study explained to me. I have been given the information sheet.

☐

I have had the chance to ask questions about the study.

☐

I know that I do not have to take part in the study. I understand that I can leave the study at any time. My legal rights and medical care will not be affected.

☐

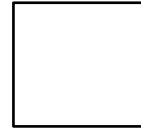
I understand that my data will be made anonymous.

☐

I understand that the interviews will be recorded.

☐

I am happy for you to use anonymous quotes from the interviews in the findings. This may be in final reports, PhD papers, conferences and in research journals.



I..... agree to take part in Camilla Dawson's research.

Signature of participant.....

Date.....

Signature of researcher.....

Appendix C- Interview schedule

Interview schedule

Participant will be informed of the following details:

Thank you for agreeing to take part in this interview. I would like to find out about your experience of your swallow therapy. I'm going to ask a few questions about what therapy you have received and what effect it had. Are you happy to continue? (these questions will be used as a prompt and will follow cues given by the participants).

I will be recording our conversation using this Dictaphone. Your information will be stored without using your name, so none of your information will be identifiable. This interview is confidential between yourself and the research team. Individual information will not be shared with the clinical team, so you can feel confident about discussing your experiences. If you disclose any information which may be of harm to yourself or someone else, this confidentiality will be broken, so the information can be passed on to the appropriate team to support you. If you would like to write anything down because talking is difficult there are pens and paper available for you. You can stop or withdraw your consent at any time.

1. Have you met a speech and language therapist?

2. When did you first meet her?

3. What happened?

(prompt: what did you talk about?)

4. What did that feel like?

5. How have you felt since your surgery?

(prompts :how prepared did you feel? who helped? what did you expect?)

6. What problems have you encountered since your surgery?

(prompt: has your communication or swallowing changed?)

7. Did the session with the speech and language therapist help prepare you for these problems?

(Prompt: have the discussions or support you received changed how you have felt?)

8. How?

9. What do you think could have helped?

10. Have you seen the speech and language therapist again?

11. What happened then?

12. Was that helpful?

13. What else could have helped?

(Prompt-can you think of different things that may have been helpful? Why would that be helpful?
What would tell you that had helped?)

14. Did the SLT speak with your family or friends whilst you were in hospital?

15. Can you tell me about the ways the SLT had an impact on your recovery in hospital?

16. How do you feel now?

17. What other support would you have liked?

18. What else would you like to add?

Ethics number (ERGO) 12133

IRAS number 164120

Version

Appendix D- Levels of evidence

Level	Therapy / Prevention, Aetiology / Harm	Prognosis	Diagnosis	Differential diagnosis / symptom prevalence study	Economic and decision analyses
1a	SR (with homogeneity*) of RCTs	SR (with homogeneity*) of inception cohort studies; CDR" validated in different populations	SR (with homogeneity*) of Level 1 diagnostic studies; CDR" with 1b studies from different clinical centres	SR (with homogeneity*) of prospective cohort studies	SR (with homogeneity*) of Level 1 economic studies
1b	Individual RCT (with narrow Confidence Interval"i)	Individual inception cohort study with > 80% follow-up; CDR" validated in a single population	Validating** cohort study with good" " " reference standards; or CDR" tested within one clinical centre	Prospective cohort study with good follow-up****	Analysis based on clinically sensible costs or alternatives; systematic review(s) of the evidence; and including multi-way sensitivity analyses
1c	All or none	All or none case-series	Absolute SpPins and SnNouts" "	All or none case-series	Absolute better-value or worse-value analyses
2a	SR (with homogeneity*) of cohort studies	SR (with homogeneity*) of either retrospective cohort studies or untreated control groups in RCTs	SR (with homogeneity*) of Level >2 diagnostic studies	SR (with homogeneity*) of 2b and better studies	SR (with homogeneity*) of Level >2 economic studies
2b	Individual cohort study (including low quality RCT; e.g., <80% follow-up)	Retrospective cohort study or follow-up of untreated control patients in an RCT; Derivation of	Exploratory** cohort study with good" " " reference standards; CDR" after derivation, or validated	Retrospective cohort study, or poor follow-up	Analysis based on clinically sensible costs or alternatives; limited review(s) of the evidence, or single

		CDR" or validated on split-sample\$\$\$ only	only on split-sample\$\$\$ or databases		studies; and including multi-way sensitivity analyses
2c	"Outcomes" Research; Ecological studies	"Outcomes" Research		Ecological studies	Audit or outcomes research
3a	SR (with homogeneity*) of case-control studies		SR (with homogeneity*) of 3b and better studies	SR (with homogeneity*) of 3b and better studies	SR (with homogeneity*) of 3b and better studies
3b	Individual Case-Control Study		Non-consecutive study; or without consistently applied reference standards	Non-consecutive cohort study, or very limited population	Analysis based on limited alternatives or costs, poor quality estimates of data, but including sensitivity analyses incorporating clinically sensible variations.
4	Case-series (and poor quality cohort and case-control studies\$§)	Case-series (and poor quality prognostic cohort studies***)	Case-control study, poor or non-independent reference standard	Case-series or superseded reference standards	Analysis with no sensitivity analysis
5	Expert opinion without explicit critical appraisal, or based on physiology, bench research or "first principles"	Expert opinion without explicit critical appraisal, or based on physiology, bench research or "first principles"	Expert opinion without explicit critical appraisal, or based on physiology, bench research or "first principles"	Expert opinion without explicit critical appraisal, or based on physiology, bench research or "first principles"	Expert opinion without explicit critical appraisal, or based on economic theory or "first principles"

Produced by Bob Phillips, Chris Ball, Dave Sackett, Doug Badenoch, Sharon Straus, Brian Haynes, Martin Dawes since November 1998. Updated by Jeremy Howick March 2009.

Appendix F- Participant demographics

	Name	Age	Marital status	Children	Occupation	Ethnicity	Previous cancer?	Type of reconstruction	Days in hospital
P1	Mary	68	Married	No	Retired	White-British	No	Tracheostomy, neck dissection, Maxillectomy (roof of mouth), including orbital floor (the floor of the eye socket). Reconstructed using titanium plate and thigh flap.	17
P2	Annie	75	Widowed	Yes	Retired	White-British	No	Tracheostomy, Maxillectomy (roof of mouth) and left neck dissection, reconstructed with radial forearm flap.	9
P3	Sandra	63	Single	Yes	Retired	White-British	Yes	Tracheostomy, floor of mouth resection and reconstruction with scapula flap.	12
P4	Emma	63	Married	Yes	Employed	White-British	No	Tracheostomy, neck dissection, mandible resection, reconstruction with fibula flap.	11
P5	Mike	65	Married	Yes	Employed	White-British	No	Tracheostomy, right neck dissection resection of mandible (jaw bone), and reconstruction with fibula flap.	10
P6	Melanie	49	Divorced	Yes	Employed	White-British	Yes	Tracheostomy, excision tongue cancer, neck dissection, reconstruction with thigh flap.	18
P7	Andrew	63	Married	Yes	Employed	White-British	Yes	Tracheostomy, excision floor of mouth tumour, radial forearm free flap, abdominal skin graft.	12
P8	Maria	68	Married	Yes	Employed	White-Other	No	Tracheostomy, resection mandible (jaw bone), neck dissection and reconstruction with fibula flap.	21
P9	David	50	Single	No	Employed	White-British	No	Tracheostomy, resection floor of mouth and rim of mandible (jaw bone). Reconstruction with radial forearm free flap, abdominal skin grafts.	11
P10	Simon	73	Married	Yes	Retired	White-British	No	Tracheostomy, resection mandible (jaw bone) tumour, neck dissection, reconstruction with deep circumflex iliac	12

								artery free flap (hip bone flap).	
P11	Steve	48	Married	Yes	Employed	White-British	No	Tracheostomy, bilateral neck dissection, partial tongue removal , dental clearance and reconstruction with radial forearm flap.	16
P12	Eleanor	73	Married	Yes	Retired	Black-Other	No	Tracheostomy, resection of tongue tumour, radial forearm free flap, abdominal skin graft.	10
P13	John	53	Married	Yes	Retired	White-British	No	Tracheostomy, neck dissection, hemi-maxillectomy (half of roof of mouth), lower dental extractions, reconstruction with hip bone flap.	12
P14	Edward	60	Married	No	Employed	White-British	No	Tracheostomy, neck dissection, segmental mandibulectomy (partial removal of jaw bone), reconstruction with fibula flap.	14
P15	Siraj	71	Married	Yes	Employed	Asian-British	No	Tracheostomy and neck dissection, partial tongue removal and reconstruction with left radial forearm	10

Appendix G- Theme generation

I never dreamt	'like this for the rest of my life'	'Voicelessness'	<p>'I wondered if I'd ever get my voice back to how it was before' (Mary-line 199)</p> <p>'can you imagine me to feel not be able to speak ever again cause that's what I thought, I thought it's just a pen and a paper' (Maria-line 46)</p> <p>'The worst part erm immediately post-surgery was being locked in your own body not being able to converse' (Emma- line 215)</p> <p>'when I first tried to talk nobody could understand me at all and I found it very frustrating' (Mary-142)</p> <p>'but I couldn't tell her, and she didn't really want to know' (Mary line 268)</p> <p>'you've got your own voice, to voice your opinion, it's hard not being able to talk, put somebody that can talk, like yourself in the position for two or three days and tell em they can't talk at all [3 seconds] its strenuous' (Sandra-403)</p> <p>'I was frightened in case I couldn't talk or make myself understood and I was worried in case I might be like that forever' (Sandra line 37)</p> <p>'I was giving signals and id got a sheet of paper with A B C D on and spelling out words and of course you know when people spell words they can't spell' (Mike line 88)</p>
		'Just soft flesh'	<p>'it feels like I've got er raw sausages in my mouth' (David line 47)</p> <p>'I mean my ear feels like it doesn't belong to me it's just it kind of hurts' (Emma line 200)</p> <p>'this side just feels like nothing at all its just soft flesh' Maria line 122</p> <p>'I don't care whether I'm like metal mickey, Frankenstein, I'm alive and breathing and glad to be here' (Sandra line 338)</p>
		'How I look when I talk'	'I mean people may think oh my god [laughs]if I look like that I'm not

			<p>going to have that operation' (Edward-line 71)</p> <p>'I am not going to want to go out and see people if I'm going to look like this for the rest of my life' (Emma- line 131)'. I was scared to go out'(Melanie-line 212)</p> <p>I'm not going down stairs 'cause I'm embarrassed at the moment about the way my face is, but I'm stopping, being on the ward, but I'm alright (Steve-line 178)</p>
	'you just do it'	'No choice'	<p>'I didn't really have a choice, it's go and have it done [crying]' (Emma-line 145)</p> <p>'I know I didn't have any treatment left to me, if I didn't go for, that was radiotherapy and that is not cure that is only for to stall things and give you a bit more time' (Mary- line 73)</p> <p>'if it's got to be done it's got to be done' (Simon-line 204)</p>
		'Search for strength'	<p>'I could, if it wasn't for [husband]...I could have left the op' (Emma-101)</p> <p>'my mother didn't struggle to give birth to me, to struggle to put clothes on my back for me to give up' (Sandra-347).</p> <p>'I pray and say please God help me to pull through' (Maria-line 192), 'I put faith in my God who has pulled me through and bought me back safe and sound' (Siraj-line 29)</p> <p>'I didn't want to lose my independence whilst I've got it' (Mary line 137)</p> <p>'it's a fight, a fight and a struggle' (Sandra line 345)</p>
	'It's a journey'	'How rough it would be'	<p>'I knew it was going to be a long fight but I didn't realise how rough it would be' (Mary-108)</p> <p>'I lay there and I just feel so wretched' (Emma-247)</p> <p>'I will have down moments and I'll probably go home and cry my eyes out' (Emma-388)</p> <p>'Mr average in the street don't know a thing' (Mike-237)</p>

			<p>'it's harder than you think' (David-23)</p> <p>'obviously you're a bit more traumatised than you think you will be (Andrew-34)</p> <p>'some days you feel shit' (Mike-47)</p> <p>'I feel completely exhausted' (Maria-229)</p> <p>'This time I think I've found it harder not because it was different but because I'm older' (Sandra-46)</p> <p>'I felt that was the end of my life' (Maria-43)</p> <p>'people will say well at least you're alive, yes but I want to be alive in the best way I can' (100-Emma)</p>
		'you come out of it'	<p>'it's getting better now by the day' (David-186)</p> <p>'it'll probably take two to three months to you know fully heal so that's that's fine, I've no problem with that' (Simon-66)</p> <p>'it will continue to just get better and better' (Andrew-110)</p> <p>'you get to that stage that you feel a bit more human that always helps' (Emma-395)</p> <p>'the body adjusts (Emma-108)'</p> <p>'I'd never thought of this this this point of it or part of it being like a journey but it is a journey' (Mike-283)</p> <p>'I feel fine at the moment, when I get home and all that, get back to a routine and then get myself together , but at the moment im in a good place, im not in a bad place' (Steve-369)</p> <p>'proud of myself, I'm proud of everybody helping me yeah, I feel I've managed to get through it yeah' (Mary 309)</p> <p>'like I'm an even stronger person, everybody said I can't believe how, what a tough cookie I am' (Mary 361)</p> <p>'I know it's going to take months really but it'll be like day after day, week after week you know what I mean and then there will come a</p>

			<p>time where ill I think it will be so gradual that I probably won't notice, you know I won't be able to go oh you know, cause it will be so gradual' (Melanie-309)</p> <p>'I have to go home first and then there's a, a recovery period, I don't know how long at the moment, depends how it goes' (Simon-199).</p> <p>'I said when I came in, I came in on the dark side and I'm coming out on the light side, and its happened' (Annie-150)</p>
		'you're not going to take this on board'	<p>"you're not going to take this on board [1 second] you're not you won't" (David line 29).</p> <p>"I don't think you can, I don't think you can prepare people er by just sitting down and saying well you're going to experience this and this is a consequence, yeah you hear the words and er I think it's important to go through that, that erm er that process but obviously er until you've done it it doesn't mean very much' (Edward-53)</p> <p>'they can't tell you what is going to happen to you definitely, but they give you a kind of a rough outline, which I can't expect any more' (Melanie line 165)</p> <p>'I wasn't prepared at all, because it was only two weeks from finding out, to do it' (Maria line 72)</p> <p>'I don't think anything could prepare you for this, no, but they've all reassured me it will get better" (Steve line 203)</p>
They look at you and they speak to you	'You've got to be able to connect'	'that people have the time'	<p>'we took a lot of their time that day they were all, nobody looked at the clock' (Emma- 283)</p> <p>'cause I've only seen her probably about two or three times [unintelligible] so maybe er once a day or, it's not going to harm... I might be talking better now if id had it more often' (Steve-211).</p> <p>'he's just so nice, calming, relaxing they all are they make you just feel at ease, he's been brilliant, hundred, hundred percent you know I'll</p>

			<p>have to, yeah ill really remember him, I owe him a lot, he's given me he's given me that confidence and time' (David-369)</p> <p>'you don't expect it these days, that people have the time' (Andrew-30)</p>
		<p>'they really want you to get better'</p>	<p>'whoever came to me and did whatever they did, were were kindness itself' (Annie-46)',</p> <p>'you're not just there to give someone their medication, to take their blood pressure and you know you've got to be able to connect' (David-304)</p> <p>'they always are coming back and being here and talking things through and answering questions and things like that' (Mary 298)</p> <p>'as people asked me questions id sort of answer it and I'd answer it and she'd (the SLT) give the the same answer but her answers were absolutely a hundred percent smack on with what what I was trying to say, yeah an if it weren't quite right then I must of given a gesture or a nod or a shake and she'd change it an to exactly wha what it was [begins to cry] I only met her for a couple of minutes [crying] but really yeah but she was a really really big help' (Mike-138)</p> <p>'they've (the SLT) been very caring and thoughtful and caring about you and what you need so if there is anything you want and giving you you know sort of a blank sheet you know anything you need you ask and you'll get so yeah, very open' (Melanie-277)</p> <p>'that's how she (the SLT) talks you through everything she's like, she's like part of your family, you're so relaxed laid back' (Sandra-252).</p> <p>'I'd built up a lovely rapport with B' (Sandra-215)</p> <p>'their beautiful people you know' (David-355)</p> <p>'Its absolute generosity' (Maria-99)</p> <p>'the thing that impressed us both erm that's both me and my wife erm of our interactions with er [consultant] and since then with the team is</p>

			that the erm er complete absence of the sort of formulaic response' (Edward-135)
	'I felt like a human being'		<p>'what does help is to know you are not just a patient stuck in a bed you are still a person and they show caring and that I think goes a long way for most people' (line 372-Emma)</p> <p>'I know we've got hospital numbers but we are treated like individuals and they soon get to know you' (Emma-370)</p> <p>'I didn't feel like a number, I felt like a human being' (Annie 194)</p> <p>'because if they get talked to properly like everybody has talked to me properly, as a human being, as a person, shown me lots of kindness' (Sandra-307)</p> <p>'the way they spoke to me, the way they explained things' (Sandra-166)</p> <p>'talk to you they talk to you not round you, you know when like yourself, the doctor or anybody, they look at you, and they speak to you' (Annie-162)</p> <p>'don't talk in your language talk in our language (415)...everyone keeps going to me , the flap, the flap, I'm like what's the bloody flap...I've just taken it on board now I've got a flap in my mouth' (David-50)</p>
	'You'll find another way'		<p>'that practical advice has been has obviously been valuable and I think will continue to be useful because you know one doesn't...I've never done, had this before so you don't know what to expect on a day to day basis and how best to manage with practical things like eating and how eating is effected by the developing scenario in the mouth' (Edward line 40)</p> <p>'they told me about the best part to, er the best part of the tongue and mouth to swallow with before swallowing' (Steve line 33)</p> <p>'they were er, very thorough really, very good' (Steve line 39)</p> <p>'I think she did make me feel better saying I could go from the puree to</p>

		<p>the mashable, I think she understood the diet' (John line 82)</p> <p>'because with the speech therapist it's like oh you're going for an exercise today' (Eleanor line 421)</p> <p>'I still feel that I should have been given lessons by the speech therapist because she felt that my speech is good, she decided not to give me any further advice' (Siraj-60)</p>
	<p>'Give me your life into my hands and I'll look after you'</p>	<p>'she reassured she's going to look after me, a lady only that small, beautiful lady and she says, I'll look after you, just give me your life to my hands and I'll look after you' (Maria-76)</p> <p>'when I've got upset there's somebody there to put their arm round me, and tell me I'm going to get through it, and I'll get there' (Mary-334)</p> <p>'from the time when you opened your eyes in the morning, until you closed them at night there was somebody, a nurse, a doctor, a speech therapist' (Annie-63)</p> <p>'even the young girls, but everybody everybody , I don't know if it's their second senses or if they are like that with everybody but with me they were' (Maria-103)</p> <p>'I've never known a hospital like it for being there I haven't had this experience in other hospitals'(Mary-353).</p> <p>'staff at the ward were excellent, they looked after me like a little baby' (line 33 Siraj)</p>

Table 2- Examples of exclusion

Name of paper	Reason for exclusion
Pharyngoesophageal stricture after treatment for head and neck cancer.	Oncology only not speech and swallow therapy specific
Dental rehabilitation after surgery for oral cancer	Non swallow specific
Management of oropharyngeal Dysphagia in laryngeal and hypopharyngeal cancer.	Surgical study
Dynamic MRI analysis of tumor and organ motion during rest and deglutition and margin assessment for radiotherapy of head-and-neck cancer	Non swallow specific
Objective assessment of swallowing function after definitive concurrent (chemo)radiotherapy in patients with head and neck cancer	Instrumental intervention
Priorities for the head and neck cancer patient, their companion and members of the multidisciplinary team and decision regret	Non behavioural
Swallowing function following postchemoradiotherapy neck dissection: review of findings and analysis of contributing factors	Incidence of dysphagia
Risk of aspiration following radiation for non-nasopharyngeal head and neck cancer.	Oncology only not speech and swallow therapy specific
History of voice rehabilitation following laryngectomy.	Non swallow specific
Phase II trial of the histone deacetylase inhibitor vorinostat (Zolinza, suberoylanilide hydroxamic acid, SAHA) in patients with recurrent and/or metastatic head and neck cancer.	Oncology only not speech and swallow therapy specific
Reliability and validity of the Vanderbilt Head and Neck Symptom Survey: a tool to assess symptom burden in patients treated with chemoradiation	Dysphagia outcome measure

Reference	Country	Study design	Population	Measure	Intervention	Reported outcome
Blyth et al. (2015) Level 1 evidence	Australia	Systematic review of 7 articles. Behavioural interventions for speech and/or swallowing dysfunction following partial oral tongue surgery.	N=133 All included studies used sample sizes >50. Three studies single case reports, 4 studies explored speech not swallow.	Video fluoroscopy, Nasendoscopy, Surface electromyography, MD Anderson Dysphagia Inventory.	Behavioural exercises including: Mendelsohn and effortful swallow, postural modification, tongue and jaw range of movement exercises.	Reduction of aspiration and pharyngeal residue on VFS, Removal of NG feeding tube Increased muscular peak on SEMG, Return to full oral intake for 3/6 oral tongue patients, Improvement in MD Anderson Dysphagia scores from pre to post in experimental group.
McCabe et al. (2009) Level 1 evidence	USA	Systematic review Behavioural interventions for swallow therapy following cancer treatment.	N=60 31/60 with head and neck cancer, 6/31 surgery alone, 1/31 chemotherapy alone 7/31 radiation alone, 7/31 surgery and radiation therapy.	Video fluoroscopy, manometry to measure swallow pressures.	Behavioural exercise including: Mendelsohn and effortful swallow, and postural modifications.	Reduced amount of residue within oropharynx post swallow, improved duration and pressure of swallow musculature, improved functional oral intake scores.
Carnaby-Mann et al. (2012)	USA	RCT Participants underwent radiotherapy treatment for head and neck	n = 58 Case = 20 Sham = 18 Control = 20	Muscle size and composition measured by MRI, Functional	Behavioural exercise Prophylactic exercise, jaw strengthening,	Prophylactic exercise intervention group, improved preservation in T2 weighted MRI scores, functional

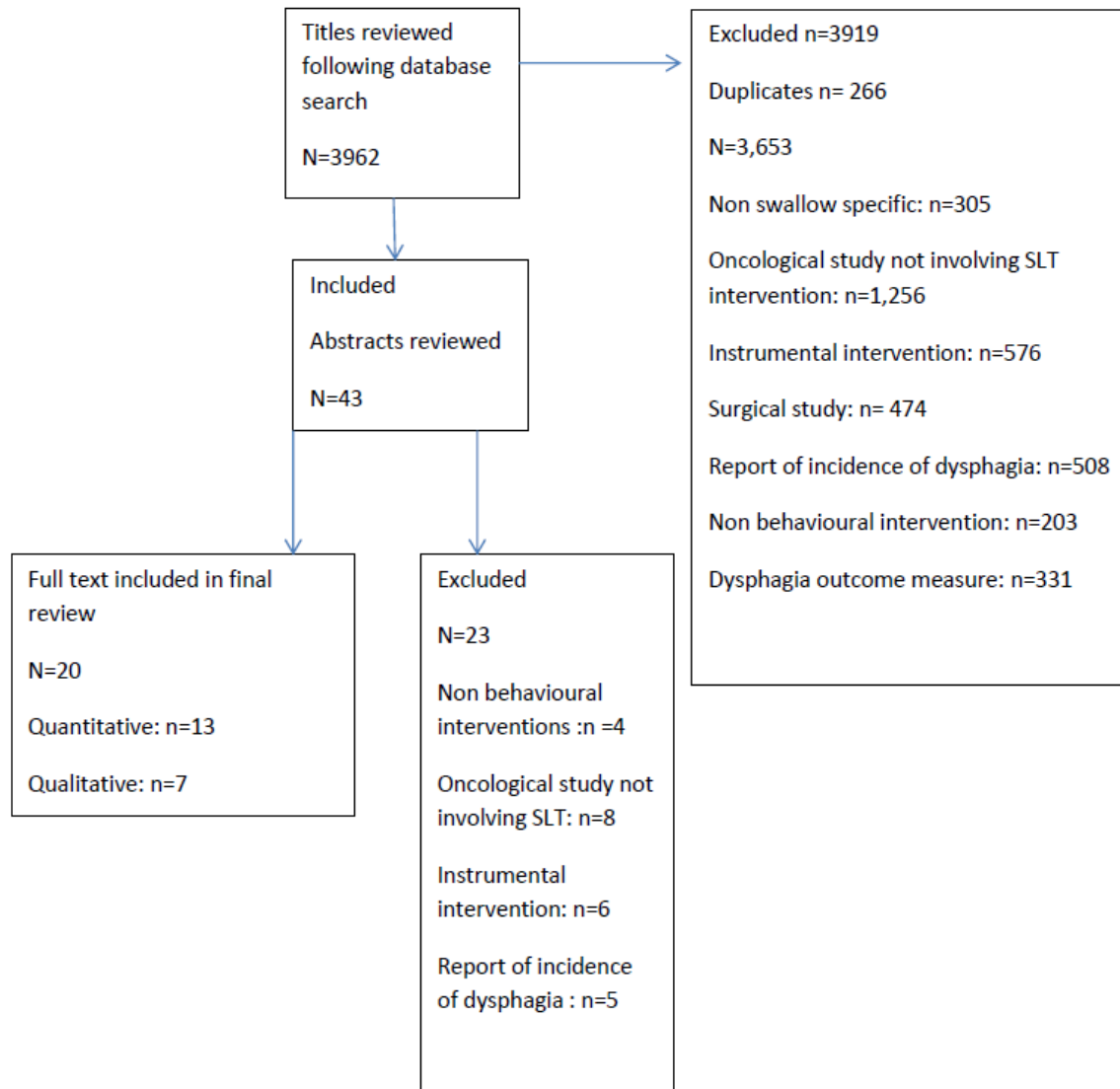
Level 1 evidence		cancer.		swallowing Ability, Mouth opening, Chemosensory function, Salivation Nutritional status, Occurrence of dysphagia-related complications.	effortful swallow, tongue exercise.	swallowing, mouth opening, taste and salivation. Mean standardized difference (t2 value mylohyoid)a Cohen's d = -0.36 (95 % CI -0.098 to 0.26)
van der Molen et al. (2014) Level 3 evidence	Netherlands	Clinical trial Participants underwent radiotherapy treatment for head and neck cancer	n=29 Case=15 Control=14	Videofluoroscopy, study-specific questionnaires post treatment (10 weeks, 1 year, and 2 years)	Behavioural exercise Gargling, jaw stretching, laryngeal elevation exercises, tongue base exercises.	In first year post chemo radiotherapy all treatment symptoms reduced except xerostomia (59 %). Only significant difference was weight gain at 2 years in experimental group (p = 0.002).
Kotz et al. (2012) Level 3 evidence	USA	Case control Participants underwent radiotherapy treatment for head and neck cancer.	n = 26 Case = 13 Control = 13	Functional oral intake score, performance status scale, feeding tube placement Recorded at time points, baseline, immediately after radiotherapy, and at 3, 6, 9, and 12 months after radiotherapy.	Behavioural exercise Effortful Swallow, tongue base retraction exercises, effortful swallow technique, and the Mendelsohn manoeuvre.	-no significant differences between groups immediately after radiotherapy or at 9 or 12 months. Improved function was noted at 3 (p=0.03) and 6 month assessments (p=0.009) in the case group.
Denk et al.	Austria	Case series, pre and	n=32	ENT examination,	Behavioural exercise	-Successful rehabilitation for

(1997) Level 4 evidence		post. Participants underwent surgical treatment for head and neck cancer.		video-endoscopic swallowing study , video fluoroscopy. Recorded at time points before and after functional swallowing therapy.	Ice stimulation of swallow reflex, lip tongue and swallow exercises, posture and diet modification	75% of participants who regained full oral intake after surgery.
Zhen et al. (2012) Level 3 evidence	China	Non-randomized controlled trial Participants underwent surgical treatment for head and neck cancer.	n=46 case=23 control: 23	MD Anderson Dysphagia Inventory	Behavioural exercise Diet modification; environmental arrangement; positioning (including chin-down and head rotation); compensatory swallowing strategies, including the Mendelsohn manoeuvre (sequential swallow) and effortful swallow.	Improved global MD Anderson Dysphagia Inventory scores in case group (p=0.01)
Logemann et al.	USA	Randomised clinical trial Participants underwent	n=19 case=8	Video fluoroscopy	Behavioural exercise Shaker exercise-	Greater reduction in post- swallow aspiration in the

(2009) Level 3 evidence		surgery and or chemoradiotherapy or presented with stroke.	control=11		based on the upward and forward movement of the hyo-laryngeal Structures.	case compared with control group (p = 0.028).
Lazarus et al. (2014) Level 3 evidence	USA	Randomised clinical trial Participants underwent radiotherapy with or without chemotherapy.	n=23 case=11 control=12	QOL outcome measures, measures of tongue strength, clinician rated measure of swallow efficiency	Behavioural exercise Tongue strengthening exercises	No differences in outcomes between groups.
Nguyen et al. (2007) Level 4 evidence	USA	Case series, pre and post. Participants underwent chemoradiation (n=24) or post-operative radiation therapy (n=17).	n=41	Modified barium swallow	Behavioural exercise Diet modifications, Swallow manoeuvres	13 patients (32%) demonstrated improvement in dysphagia severity. 7/13 received chemoradiation, 6/13 received post-operative radiotherapy.
Hutcheson et al. (2013) Level 4 evidence	USA	Case series Participants all underwent radiotherapy or Chemoradiation.	n= 497	Length of gastrostomy dependence; adherence to swallow exercises, diet taken via mouth.	Behavioural exercises Hyo-laryngeal excursion, airway protection, tongue base retraction, jaw stretch, yawn, gargle, and effortful swallows.	58% participants reported adherence to the swallow exercises. Participants who managed some diet through Chemo-radiotherapy or radiotherapy maintained a normal diet through long term survivorship (around 22 months). 65% who didn't eat or exercise also returned to a regular diet after treatment.

Zuydam et al. (2000) Level 4 evidence	UK	Case series Participants all underwent surgery	n=13	Video fluoroscopy	Behavioural exercise Chin tuck and effortful swallow.	Descriptive statistics used, due to small sample size. Strategies effective in 50% of people who aspirated, most effective between one and six months post-surgery.
Carnaby-Mann and Crary (2010) Level 4 evidence	USA	Case-control 18 Participants had undergone treatment for head and neck cancer (no detail of previous treatment type) 4 had neurological injury.	n=24 case=8 control=16	Functional oral intake scores, presence of tube feeding, video fluoroscopy.	Behavioural intervention Intensive muscle strengthening protocol	Dysphagia reduced by 69% in case group, both approaches resulted in functional improvements.

Figure 1-Inclusion and exclusion



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