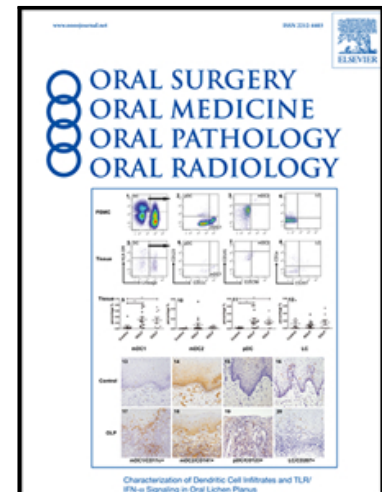


The experiences of people who receive swallow therapy following surgical treatment of head and neck cancer

Camilla Dawson DClinP ,  
Jo Adams PhD. Professor of Musculoskeletal Health ,  
Deborah Fenlon PhD. Professor of Nursing

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

Corresponding author: Camilla Dawson, DClInP, Queen Elizabeth Hospital Birmingham.

Camilla.dawson@nhs.net

Jo Adams, PhD. Professor of Musculoskeletal Health, University of Southampton.

Deborah Fenlon, PhD. Professor of Nursing, Swansea University.

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## Abstract

**Purpose:** This research was initiated to explore the experiences and important elements of swallow therapy in people following surgery for treatment of head and neck cancer.

**Methods:** One to one, face to face interviews were conducted with people with head and neck cancer post oral reconstructive surgery (free, pedicled or bony flap), 7-14 days post-surgery. Analysis was conducted using interpretive phenomenology.

**Results:** Analysis of interviews from 15 patients identified two overarching themes: 'I never dreamt' and 'They look at you and they speak to you'. There was no way to adequately prepare for the enormity of surgery and its consequences, however the way health professionals interacted and communicated with the person, rather than their altered and disfigured selves was healing and therapeutic.

**Conclusions:** Novel ways to prepare people for head and neck cancer surgery, and support in recovery are required, including ways to connect and help people feel human again.

## Introduction

Head and neck cancer (HNC) is the sixth most common cancer worldwide [1]. Both the disease and its treatment pose specific challenges to the individual. The location of tumour within the face, mouth or neck, means that cosmetic alteration caused by the disease or treatment can be difficult to hide or disguise. Alongside this, there may be notable impact of the disease on an individual's ability to speak, eat and drink. They may experience social withdrawal, avoiding meals with family and not returning to work following treatment [2] which in turn effects fundamental components of being human.

The relationship between compromised quality of life and poor swallow function (dysphagia) has been established [3], and people with swallowing problems define this as a priority for them

following treatment [4]. The Speech and Language Therapist (SLT) assess, diagnose and manage disorders of swallow and communication. Their inclusion in the care of people with HNC is considered a core requirement of HNC services within the UK [5]. As the burden associated with reduced swallow and speech function has been recognised[6], research has begun to explore how particular oncological and surgical treatment interventions may reduce impact on function[7, 8]. This has included reducing toxicity to structures involved in the mechanism of swallow[9], and surgical approaches to limit motor and sensory dysfunction [10]. Similarly, swallow research has explored ways rehabilitation interventions can improve swallow physiology, involving postural adaptations, techniques to improve swallow competence such as swallow manoeuvres by directing food or drink via intact musculature rather than anatomy that may have been altered by disease or surgery [11], respiratory swallowing coordination [12] and expiratory muscle strength training [13].

An important development in the field is the study of adherence to these novel rehabilitation regimens, in order that the effects of dysphagia therapy on swallow outcomes and ultimately a person's ability to manage their own nutrition and hydration may be better understood [14]. Available evidence suggests rate of adherence to dysphagia therapy interventions is 21.9%-51.9% [14]. Whilst behaviour change techniques have promoted adherence to swallow therapy interventions[15], there remain unanswered questions about how individuals with dysphagia experience and perceive the value of dysphagia therapy. This is of particular relevance to individuals who receive intensive swallow therapy after HNC surgery, as swallow rehabilitation is likely to form a significant component of their post-operative recovery.

The majority of available research is quantitative, exploring swallow rehabilitation following chemotherapy or radiotherapy treatment rather than surgery. The small volume of qualitative data about the individual's experience also exists mainly within the field of chemo and radiotherapy treatment of HNC[16-18] . There are no studies which explore the individual's experience of dysphagia therapy in the immediate post-surgical period. As the SLT spends a significant time with

the individual following surgery providing swallow rehabilitation, this study was undertaken to consider how this therapy may effect clinical outcomes and potentially alter the individual's experience of their disease and treatment.

The gaps in the research available around swallow rehabilitation following HNC treatment are problematic. Firstly, as there is little information which identifies what theories or frameworks underpin rehabilitation, our ability to understand *how* therapeutic processes may impact an individual's recovery is limited. Secondly, the majority of studies focus on physiology of swallow, without considering the individual's perceptions of the process. Questions around how quality of life outcomes may be enhanced following swallow therapy remain unanswered, as there has been very limited direct research engagement with this patient population.

To answer this research needs to move beyond simply identifying the relationship between poor swallow and compromised quality of life. Individual and experiential facets of swallow therapy interventions may be more effectively captured within an interpretivist paradigm, to expose how and why people respond to various dysphagia treatments. The individual's belief and perceived value of therapeutic interventions has been identified as an important facet of their adherence [19], therefore it is important to determine how swallow rehabilitation may be received by the individual and why they believe it may or may not be of value. This information could facilitate improved understanding of the needs of people following HNC surgery and tailor therapy appropriately, optimise adherence to swallow recommendations, and ultimately help support the individual to enhance their functional outcomes.

Work by Frank [20], Carel [21] Kalanithi [22] and Little [23] 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. The person with HNC

was positioned centrally to this research enquiry so their experiences can begin to shape and develop interventions in a meaningful way.

## **Materials and methods**

This was an interpretive phenomenological study. In-depth, semi-structured, 1:1, face to face interviews with people who received swallow therapy following surgical treatment were used. Participants were asked the same eighteen questions, which sought information about their swallow, their swallow rehabilitation, the team providing therapy, and their experience of their recovery. Prompts included phrases such as; “how prepared did you feel? who helped? what did you expect? What else may have helped? How did you know?”

Written consent was obtained from participants before inclusion in the study. Full ethical approval was granted from the University of Southampton Ethics and Research Governance Online (reference: 12133) and NHS Integrated Research Application System (IRAS reference: 164120). To ensure the confidentiality of participants, names were changed in the reporting data.

All procedures performed involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

## **Sample**

Eligible participants were identified by the clinical nurse specialist (CNS) and surgeon at the weekly Multi-Disciplinary Team (MDT) meeting. Patients requiring reconstructive surgery with free, pedicled, or composite flap for oral cavity cancers, over 18 years old, could understand and communicate in English, and had capacity to consent within the study centre were included. Those receiving reconstruction for benign oral cavity disease (e.g., Osteoradionecrosis ) or had any cognitive impairment were excluded.

***Patient involvement***

Patient involvement was included from the commencement of the study. A patient diagnosed with HNC, who had undergone surgery and swallow therapy reviewed study procedures helped develop the pilot and informed the interview schedule. This patient was a part of a UK Cancer Network advisory group, who offered support and review of documents pertaining to research involving people who had undergone HNC treatment.

***The interview***

The interviews took place whilst the participant was an inpatient after having surgery, receiving swallow therapy, before being discharged home, between day 7-14 after their operation. In the UK it is standard that people remain in hospital for 7-14 days after major HNC surgery and receive swallow therapy from the SLT during this time. The interviews took place on the inpatient ward in a quiet, private room to ensure confidentiality. The interviews were audio recorded and conducted by the researcher. The researcher (CD) is an SLT in the study centre. To reduce the potential of bias, she did not provide any therapeutic interventions to eligible participants during the recruitment phase. Four other SLTs provided swallow therapy to the participants according to standard clinical practice within the institution.

Although the researcher was prepared to communicate with participants with no voice or limited vocalisation by the use of pen and paper, or lip reading, this was not required during the interview. However, many participants had altered speech and their intelligibility was at times challenging. At these points the interviewer (CD) asked for clarification of words or phrases, to limit potential for misunderstanding.

***Analysis***

An inductive approach was used to analyse the data to ensure the emergence of themes specific to the experience of dysphagia post- surgery. The data were transcribed verbatim, coded line by line by CD, phrase by phrase, to their smallest meaningful component. In some cases this may have been

four words, for example 'I am a fighter'. These phrases were then semantically grouped, and tested for inter-rater reliability by the research team (CD, DF and JA). These groups became the categories, and quotes from the interviews were used as names for these categories. Categories 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 (see table 1).

## **Results**

### ***Participants***

Fifteen participants were included in the study (7 female, 8 male, median age 62.8 years, range 48-75 yrs). Length of stay ranged from 9-21 days (median 13 days) and type of reconstruction participants received included fibula flaps, radial forearm free flaps, anterolateral thigh flaps, a scapula flap and deep circumflex iliac artery flaps (see table 2).

The study sought to explore the experiences of people who underwent swallow therapy, however other complex data regarding the experience of having surgery, relationships that formed during the inpatient stay, and the physical challenges people faced were identified. Many people described their swallow competence in relation to their overall recovery. There were two overarching key findings from this study. The first, represented by the finding 'I never dreamt', was that people found HNC surgery more challenging than they could possibly have imagined. This theme encapsulated the way surgery changed the individual who existed before the operation to a new, altered version of themselves, who 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. The theme identified the way health professionals were able to look past the surgery and connect with the person behind the disfiguring intervention. In this way clinicians were able to connect with the



individual and provide a safe space for recovery to begin, whilst acknowledging the individual's humanity at a time they reported it was challenged.

### **I never dreamt**

Participants felt that there was no way they could be adequately prepared for the enormity of what would happen to them. Participants valued the preparation they were given, but this was largely about physical changes and potential symptoms. Participants were less prepared for the challenges to sense of self and personhood that they faced.

*"I don't think you can, I don't think you can prepare people by just sitting down and saying well you're going to experience this and this is a consequence, yeah you hear the words and I think it's important to go through that, that process but obviously until you've done it doesn't mean very much"(Edward-line 53)*

### **Like this for the rest of my life**

Participants experienced alterations to their sense of self, sense of ownership of their bodies and ability to choose how they spoke, ate, or looked when they spoke. Not only was this difficult in itself and the image that they presented to the world, but it also impacted on the way they believed people would interact with them in the future in both verbal and non-verbal interactions. 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.

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

*"The worst part 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 their own body unable to communicate with those around them as they wished, being misunderstood and frightened at the potential of never being able to speak again. This sense of voicelessness was traumatic, especially in context of the surgery they had undergone. The uncertainties about long term function following surgery also resulted in feelings of vulnerability and frustration.

### ***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. The meaning of recovery didn't pertain to the biological condition, and therefore couldn't be simply measured by biological improvements. People described fluctuations experienced after surgery, where they didn't feel human or lay in bed feeling "wretched".

Participants recognised each person's surgery and reaction to surgery would be different, and 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.

*"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)*

### ***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 health professionals looked at and spoke to the person, rather than their altered and disfigured face.

*"talk to you, they talk to you not round you... the doctor or anybody, they look at you, and they speak to you" (Annie-line 162)*

It was validating to be spoken to as a person and not as a wounded body [20]. This was particularly important when the participant had no voice with which to communicate, in the time immediately

post-surgery when they had a tracheostomy and severely altered speech. To have someone look directly at the individual and interact with them rather than looking at the surgery or disfigurement, 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 the MDT (the SLT, surgeon, and nursing staff) gave them time and space for this altered and specific type of communication.

*"they always are coming back and being here and talking things through and answering questions and things like that" (Mary- line 298)*

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 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.

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

### ***I felt like a human being***

A positive component of the relationship which formed between the health care professional and the individual developed in part from the capacity of the professional to view 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 physical changes without judgement or personal cost. It appeared 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.

*“I didn’t feel like a number, I felt like a human being”(Annie-line 194)*

***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 this transition. The inpatient stay following surgery represented a liminal phase, where the individual was no longer the person they were, but not yet the person they would be. The hospital provided a safe space, outside of normal life, where they could begin the process of adjusting to the changes happening to them before they had to go back to being in the world again. This challenging transitional phase included issues predominantly with eating, drinking and speaking, whilst on the ward recovering from surgery, receiving rehabilitation, and awaiting discharge home.

This was an individual experience where some people seemed to want to devolve responsibility to the health care professional, whilst others developed more equal power 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 to maintain this relationship, time limited by the inpatient stay. It is important to consider whether this could become a maladaptive process if the individual became dependent on the team.

*“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-line 334)*

***You’ll find another way***

People in this study described the importance of the skill and ability of the SLT to understand them, to 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. This support enabled the individual to find another way to manage their speech and swallow after surgery. The value attributed to time spent

with the SLT and their understanding of the participants provided more than physical rehabilitation of swallow.

*“they’ve (the SLT) been very caring and thoughtful... caring about you and what you need so if there is anything you want and giving you, you know sort of a blank sheet...anything you need you ask and you’ll get so yeah, very open” (Melanie-line 277)*

## Discussion

Post-surgical dysphagia exists in a messy and complex clinical landscape, which includes lack of sleep, intrusive medical interventions and feeling overwhelmed. Whilst it may be tempting to reduce dysphagia 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 the individuals in this study described a dysphagia therapy which was supported by many influential actors and agents including the SLT, surgeon, nurses and family.

### *Implications for practice*

Participants explained the delivery of the post-surgical swallow rehabilitation was of importance, so the mode and methods met their physical and emotional needs. Optimal delivery seemed 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 specific confidence in the SLT to have a high level of understanding and skill to manage the complexities of swallow compromise. The skills of all team members, including the SLT, needed to incorporate an understanding of the nature of what makes a person feel human, perhaps to enhance the possibility of becoming a social being again and not just a functioning body after head and neck surgery. Sen [24] describes a person’s ability to do valuable acts or ‘reach valuable states of being’ in 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. It is therefore conceivable that feeling valued and listened to by the clinical team supported the individual to engage in the physical components of rehabilitation, which helped facilitate this sense of a meaningful life.

The data also demonstrate that by connecting with and enabling people to feel human again, the therapeutic relationship can be therapy in and of itself. The significant skill required to craft this relationship was built on more than a task driven agenda. It consisted of the professional's ability not just to see the individual, but to look past their alterations, to provide adequate time and quality to the communicative experiences, and to facilitate the sense of ongoing change and moving forwards beyond the point of discharge from the acute hospital.

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. Within the study institution, people attend a 'pre-treatment session' with the SLT, Dietitian and CNS, to help prepare for their forthcoming treatment. This session largely focusses on physical symptoms expected post-surgery and is standard practice in the UK [5]. Health care professionals should explore whether it is possible to prepare people in more holistic terms for the effects of their surgery, and whether there is a causal relationship between preparation pre surgery and post-surgical symptom burden. This would involve creating and testing interventions which target and attempt to support these specific experiential and existential issues, perhaps inviting people who have already undergone a similar surgery to the pre-treatment session, to provide individual insight into the lived experience. Another possibility might be to create patient videos and or written information generated from qualitative studies.

### 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 physical, emotional and social changes. It may be more appropriate for this to be delivered by someone who has previously undergone surgery, who could be an adjunct to the discussion with the health care professionals.

The data uncovered the importance of the time spent on the ward after surgery which appears to represent a safe space where healing can take place and the individual can begin the work of adapting to their new self, 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.

People who have undergone HNC surgery are likely to have a period of voicelessness post operatively. 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 the potential to silence the individual. It may be difficult and time consuming to understand disordered communication, however clinicians can avoid deceiving themselves and incorrectly believing they are providing what the individual needs[25], by checking in with them and giving them space and time.

This study identified the complex role of the SLT, who provided more than physical rehabilitation of swallow. The research demonstrated that swallowing does not exist simply as a well-defined biological entity. The participants described its inherent links to physical, social and emotional components of life. Participants described the ability of the SLT to provide interventions that

acknowledged and recognised these issues. The rehabilitation a SLT provides can support people to adapt to their post-surgical changes and alteration to sense of self. The participants described how the SLT 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 SLT within the HNC MDT. It also uncovers important detail about how the therapeutic intervention may be considered important, and of value from the perspective of the individual with dysphagia. This detail has not been described in previous research.

## Conclusion

Surgical treatment of head and neck 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 paper. This work is of importance as it provides insights into the ways clinicians may enable a sense of self to be acknowledged and restored to help create a meaningful life following head and neck cancer surgery.

## Compliance with Ethical Standards:

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**Table 1-Themes and subthemes**

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'
		'you're not going to take this on board'
'They look at you and they speak to you'	'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'	

**Table 2- Demographics**

Description n=15	Value
Average age	Median: 62.8 years Range: 48-75 years
Gender	M: 8 F: 7
Race	White, British: 12 White, other: 1 Black, other: 1 Asian, other: 1
Marital status	Married: 11 Divorced: 1 Single : 2 Widowed: 1
Employment status	Employed: 9 Retired: 6
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
Stage and site of disease UICC (7th Edition)	<ul style="list-style-type: none"> <li>• pT4 pN0 pMx pR1 SCC, right maxilla</li> <li>• pT4a pN1 pMx pR0 SCC, left mandible.</li> <li>• pT4a, pN2c, pMx,pR0 SCC floor of mouth onto tongue</li> <li>• pT4 pN0 M0 pR0 SCC Right mandible</li> <li>• pT4a pN2b pMx pR0 SCC right mandible.</li> <li>• pT3, pN0, pMx, pR1 SCC left maxilla</li> <li>• pT2, pN2b, pMx SCC right tongue</li> <li>• pT2 pN2b PMX pR1 SCC left retro molar trigone</li> <li>• pT2 pN0 pMx pR0 SCC right mandible</li> <li>• pT2 pN0 pMx pR0 right floor of mouth.</li> <li>• pT2, pN0, pMx, pR0 left tongue</li> <li>• pT1, pN0, pMx, pR0 SCC left angle of mandible</li> <li>• pT1, pN0, pMx, pR0 SCC left buccal mucosa</li> <li>• pT1, pN0, pMx, pR0 SCC left posterior tongue</li> <li>• pT1, pN0,pMx, pR0 SCC Right floor of mouth</li> </ul>