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

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Objective. This research was initiated to explore the experiences and important elements of swallow therapy in patients after surgery for treatment of head and neck cancer (HNC).

Study Design. One-to-one, face-to-face interviews were conducted with patients with HNC 7 to 14 days after oral reconstructive surgery (free, pedicled, or bony flap). Analysis was conducted by using interpretive phenomenology.

Results. Analysis of interviews from 15 patients identified 2 overarching themes: “I never dreamt” and “They look at you, and they speak to you.” There was no way for patients to be adequately prepared for the enormity of the surgery and its consequences; however, the way health care professionals interacted and communicated with the person, rather than the altered and disfigured self, was healing and therapeutic.

Conclusions. There is a need for novel ways to prepare patients for HNC surgery and to support them in recovery, including ways to connect and help patients feel human again. (Oral Surg Oral Med Oral Pathol Oral Radiol 2019;128:456−463)

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 the tumor within the face, mouth, or neck means that cosmetic alterations caused by the disease or its treatment can be difficult to hide or disguise. Besides, there may be a 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 after treatment,[2] which, in turn, affects the fundamental aspects of being human.

The relationship between compromised quality of life and poor swallow function (dysphagia) has been established,[3] and patients with swallowing problems define resolution of this as *a priority* for them after surgery.[4] The speech and language therapist (SLT) assesses, diagnoses, and manages swallow and communication disorders. Their inclusion in the care of patients with HNC is considered a core requirement of HNC services within the United Kingdom.[5] As the burden associated with reduced swallow and speech function has been recognized,[6] research has begun to explore how particular oncologic and surgical treatment interventions may reduce the impact on function.[7,8] This has included reducing toxicity to structures involved in the mechanism of swallow,[9] and opting for surgical approaches that 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 performing swallow maneuvers by directing food or drink via intact musculature, rather than via 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 so that the effects of dysphagia therapy on swallow outcomes and, ultimately, a person’s ability to manage his or her own nutrition and hydration may be better understood.[14] Available evidence suggests that the rate of adherence to dysphagia therapy interventions is 21.9% to 51.9%.[14] Although behavior 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 because swallow rehabilitation is likely to form a significant component of their postoperative recovery.

The majority of available research is quantitative, exploring swallow rehabilitation after chemotherapy or radiotherapy treatment, rather than surgery. There is a small volume of qualitative data about the individual’s experience, mainly within the field of chemotherapy and radiotherapy for HNC.[16-18] There are no studies

Statement of Clinical Relevance

This study offers clinicians an insight into the lived experience of people who undergo head and neck cancer surgery. It provides practical advice regarding ways that the postoperative phase, which can sometimes be traumatic and challenging, may be optimally managed by the clinical team.

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that have explored the individual's experience of dysphagia therapy in the immediate postoperative period. Because the SLT spends a significant time with the individual after surgery, providing swallow rehabilitation, this study was undertaken to consider how this therapy may affect clinical outcomes and potentially alter the individual's experience of his or her disease and treatment.

The gaps in the research on swallow rehabilitation after HNC treatment are problematic. First, because there is little information identifying what theories or frameworks underpin rehabilitation, our ability to understand *how* therapeutic processes may impact an individual's recovery is limited. Second, most studies focus on the physiology of swallow, without considering the individual's perceptions of the process. Questions around how quality of life outcomes may be enhanced after swallow therapy remain unanswered because there has been very limited direct research in 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 determine how and why people respond to various dysphagia treatments. The individual's belief and the perceived value of therapeutic interventions have 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 he or she believes it may or may not be of value. This information could facilitate improved understanding of the needs of patients after HNC surgery to tailor therapy appropriately, optimize adherence to swallow recommendations, and ultimately help support the individual to enhance his or her functional outcomes.

Studies by Frank,[20] Carel,[21] Kalanithi,[22] and Little[23] identified valuable experiential components of diagnosis and treatment of life-limiting illnesses by exploring the perspective of the person with the disease. These authors suggested that by listening to the patients, the processes that they 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 that his or her experiences can begin to shape and develop interventions in a meaningful way.

MATERIALS AND METHODS

This was an interpretive phenomenologic study. In-depth, semistructured, one-to-one, face-to-face interviews with people who received swallow therapy after surgical treatment were used. All participants were asked the same 18 questions, which sought information about their swallow, their swallow rehabilitation, the team providing therapy, and their experience of their recovery. Prompts included such questions 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 the National Health Service Integrated Research Application System (IRAS reference: 164120). To ensure confidentiality, the names of the participants were changed in the reporting data.

All procedures that involved human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the tenets of the 1964 Helsinki Declaration and its later amendments or comparable ethical standards.

Sample

Eligible participants were identified by a clinical nurse specialist and a surgeon at the weekly multidisciplinary team (MDT) meeting. Patients who required reconstructive surgery with free, pedicled, or composite flap for oral cavity cancers, were older than 18 years of age, had the ability to understand and communicate in English, and had the capacity to consent within the study center 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 and who had undergone surgery and swallow therapy reviewed the study procedures and helped develop the pilot and informed the interview schedule. This patient was part of a UK Cancer Network advisory group and offered support for and review of documents pertaining to research involving people who had undergone HNC treatment.

The interview

The interviews took place while the participant was an inpatient after undergoing surgery and swallow therapy and before being discharged home, between days 7 and 14 after the operation. In the United Kingdom, patients normally remain in hospital for 7 to 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 conducted by the researcher and audio recorded. The researcher (C.D.) is an SLT in the study center. 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 vocalization with the use of pen and paper or through 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 (C.D.) asked for clarification of words or phrases to avoid any misunderstanding.

Analysis

An inductive approach was used to analyze the data to ensure capture of themes specific to the experience of dysphagia after surgery. The data were transcribed verbatim, coded line by line by the interviewer (C.D.), phrase by phrase, to the smallest meaningful component. In some cases, this might have been just 4 words, for example, “I am a fighter.” These phrases were then semantically grouped, and tested for interrater reliability by the research team (C.D., D.F., and J.A.). 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, forming the subthemes. The subthemes overarched the categories, and the main themes overarched the subthemes (Table I).

RESULTS

Participants

Fifteen participants were included in the study (7 females and 8 males; median age 62.8 years; range 48−75 years). Length of stay ranged from 9 to 21 days (median 13 days), and the type of reconstruction that participants received included fibula flaps, radial forearm free flaps, anterolateral thigh flaps, a scapula flap, and deep circumflex iliac artery flaps (Table II).

The study sought to explore the experiences of patients who underwent swallow therapy; however, other complex data regarding the experience of having surgery, relationships that were formed during the inpatient stay, and the physical challenges that patients faced were identified. Many patients described their swallow competence in relation to their overall recovery. There were 2 overarching key findings from this study. The first, represented by the finding “I never dreamt” was that patients found HNC surgery more challenging than they could possibly have imagined. This theme encapsulated the way surgery changed the individual from the person he or she was before the operation to a new, altered version, 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 patient’s relationship with health care professionals at the time of surgery. The theme identified the way health care professionals were able to look past the surgery and connect with the person behind the disfigurement caused by the intervention. In this way, clinicians were able to connect with the individual and provide a safe space for recovery to begin, while acknowledging the individual’s humanity at a time, they reported, it was challenged.

Table I. Themes and subthemes

Main themes	*Subthemes*	*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 II. Demographic characteristics

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 Anterolateral thigh flap: 2 Scapula flap: 1 Deep circumflex iliac artery: 2
Average length of stay	Median: 13 days Range: 9−21 days
Stage and site of disease UICC (7th edition)	• pT4, pN0 pMx pR1 SCC, right maxilla • pT4 a pN1 pMx pR0 SCC, left mandible. • pT4 a, pN2 c, pMx,pR0 SCC, floor of mouth onto tongue • pT4 pN0 M0 pR0 SCC, right mandible • pT4 a pN2 b pMx pR0 SCC, right mandible. • pT3, pN0, pMx, pR1 SCC, left maxilla • pT2, pN2 b, pMx SCC, right tongue • pT2 pN2 b PMX pR1 SCC, left retro molar trigone • pT2 pN0 pMx pR0 SCC, right mandible • pT2 pN0 pMx pR0 SCC, right floor of mouth. • pT2, pN0, pMx, pR0 SCC, left tongue • pT1, pN0, pMx, pR0 SCC, left angle of mandible • pT1, pN0, pMx, pR0 SCC, left buccal mucosa • pT1, pN0, pMx, pR0 SCC, left posterior tongue • pT1, pN0,pMx, pR0 SCC, right floor of mouth

SCC, squamous cell carcinoma; *UICC,* Union for International Cancer Control.

"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 the preparation 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 had an impact on the way they believed people would interact with them in the future both verbally and nonverbally. Their efforts to talk and to engage in social discourse were accompanied by the significantly altered appearance, which drew attention to the way they looked rather than to 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)*

Patients described being physically unable to speak, while feeling locked in their own body and unable to communicate with those around them as they wished, being misunderstood, and being frightened by the possibility of never being able to speak again. This sense of voicelessness was traumatic, especially in the context of the surgery they had undergone. The uncertainties about long-term functioning after surgery also resulted in feelings of vulnerability and frustration.

"It's a journey"

Patients experienced a transition after surgery—no longer the persons they were, and not yet reconciled to the persons they would be. The meaning of recovery did not pertain to the biologic condition and, therefore, could not be simply measured by biologic improvements. Patients described experiencing fluctuations after surgery—that they did not "feel human" or lay in bed feeling "wretched." Participants recognized each person's surgery and reaction to surgery would be different and that at various points, the course of recovery would change and develop. Patients' experiences of the postoperative phase was difficult and turbulent, but they had a sense that they were moving forward and improving. Some 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 care professionals looked at and spoke to the person that the patient was, rather than at the 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 to communicate with, in the time immediately after a tracheostomy, with their speech severely altered. Someone looking directly at them and interacting with them, rather than looking at the surgical area or disfigurement, seemed to help the patient feel like an individual with an identity, even if he or she did not have a voice. At a time when patients felt they had lost themselves and the 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 MDT (the SLT, the surgeon, and the 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)*

It is well recognized that clinicians, in fact, have limited time and are under significant pressure. However, these data demonstrated that despite this, the clinicians were able to make patients feel that they could give them time and space. This expertise is important because 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 that formed between the health care professional and the individual developed, in part, as a result of the capacity of the professional to view the effects of surgery without having a personal reaction to them. The health care professional seemed to be able to medicalize the problems that patients had, while still being able to see the individual beyond these physical changes without judgment or personal cost. It appeared difficult for the patient to obtain this in the same way with their friends and family. The restoration of a patient's sense of identity seemed to be facilitated, in part, by his or her 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 while experiencing this transition. The inpatient stay after surgery represented a liminal phase, where the individual was no longer the person he or she was, but not yet the person he or she 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 their world again. The challenges if this transitionary phase included issues predominantly with eating, drinking, and speaking, while on the ward recovering from surgery, receiving rehabilitation, and awaiting discharge home.

This was a highly individual experience, in which some patients seemed to want to devolve responsibility to the health care professional, whereas some 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 resources to maintain this relationship and their time limited by the inpatient stay. It is important to consider whether this could become a maladaptive process if the individual became too 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"

Patients in this study described the importance of the skill and ability of the SLT to understand them and to educate them by creating iterative interventions, such as increasing the complexity of the therapy provided day by day; by 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 (the SLT) have 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

Postoperative dysphagia exists in a messy and complex clinical landscape, which includes lack of sleep, intrusive medical interventions, and feelings of being overwhelmed. Although it may be tempting to reduce dysphagia to a specific symptom, requiring a specific intervention by a specific individual to improve swallow competence, dysphagia, in fact, may exist alongside many different symptoms, requiring numerous physical, emotional, and psychosocial interventions, delivered by more health care providers than just the SLT. It is important to recognize that the individuals in this study described a dysphagia therapy that was supported by many influential actors and agents, including the SLT, the surgeon, the nurses, and the family.

Implications for practice

Study participants explained that the delivery of the postoperative swallow rehabilitation was of importance and that 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 the compromise of the swallow function. The skills of all team members, including the SLT, had 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] described, in his Capabilities Approach, a person's ability to do valuable acts or "reach valuable states of being". A person's resources, function (being and doing), capabilities (tasks that 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 encouraged 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 health care professional's ability to not just see the individual but to look past the alterations, to provide adequate time and quality to the communicative experiences, and to facilitate the sense of ongoing change and moving forward beyond the point of discharge from the acute care hospital.

Patients reported that although they could be prepared for the physical effects of the surgery, the emotional and psychosocial effects were more challenging even to consider. Within the study institution, patients attend a "pretreatment session" with the SLT, the dietitian, and the clinical nurse specialist to prepare for their forthcoming treatment. This session largely focuses on the physical symptoms to be expected after the surgery and is standard practice in the United Kingdom.[5] Health care professionals should explore whether it is possible to prepare patients in more holistic terms for the effects of their surgery and whether there is a causal relationship between preparation before surgery and postoperative symptom burden. This would involve creating and testing interventions that target and attempt to support these specific experiential and existential issues, perhaps inviting to the pretreatment session individuals who have already undergone a similar surgery to provide individual insight into their 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. First, it is unclear whether a relationship exists between preoperative preparation and reduction in postoperative symptom burden; further research is required to explore this. Second, it may be more effective before surgery to discuss and explore the existential transition patients 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, as an adjunct to the discussion with the health care professionals.

The study data revealed the importance of the postoperative time spent on the ward, which appears to represent a safe space where healing can take place and the individual can begin the work of adapting to his or her new self, before having to make adjustments to the new life once discharged from hospital. It appeared that part of the clinician's responsibility was about being with the individual, which was therapeutic, and this human relationship was of great value. It was not about simply providing therapy or information.

Patients who have undergone HNC surgery are likely to have a period of voicelessness postoperatively. This affects their ability to describe their needs and influences the way in which clinicians need to communicate with them. This relationship can be complex, and clinicians need to be mindful of the risk of silencing the individual. It may be difficult and time consuming to understand disordered communication; however, clinicians can avoid self-deception and the incorrect belief that they are providing what the individual needs[25] by checking with them and giving them space and time.

This study identified the complex role of the SLT, who provided more than the physical rehabilitation of the swallow function. The study also demonstrated that swallow does not exist simply as a well-defined biologic entity. The participants described its inherent links to the physical, social, and emotional components of life. Participants described the ability of the SLT to provide interventions that acknowledged and recognized these issues. The rehabilitation a SLT provides can support patients to adapt to their postoperative changes and the alteration to the sense of self. The participants described how the SLT was able to educate and provide iterative therapeutic interventions while being with the individual and their complex symptoms after surgery. This is a valuable skill that underpins the importance of the inclusion of the SLT within the HNC MDT. It also shows how important and valuable the therapeutic intervention could be from the perspective of the individual with dysphagia. This aspect of therapy has not been described in any detail in previous studies.

CONCLUSIONS

Surgical treatment of HNC brings changes and alterations to patients in the physical, emotional, and social spheres of life. It disrupts the way they undertake the most human of tasks: eating, drinking, speaking, and presenting their faces to the outside world. The immediate postoperative phase may represent the peak of this acute realization in the individual and requires a specific kind of intervention from health care professionals, as discussed in this article. Our study is of importance because it provides insights into the ways clinicians may enable acknowledgment and restoration of the sense of self to help create a meaningful life after HNC surgery.

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