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Patient perceptions of living with head and neck lymphoedema and the impacts to swallowing, voice and speech function

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Abstract

Head and neck lymphoedema (HNL) is common following head and neck cancer (HNC) treatment, and may contribute to numerous physical, functional and psychological symptoms. However, its impact on swallowing, voice and speech is less well understood. The aim of this study was to use interpretive description to explore patient perceptions relating to the impact of HNL on swallowing, voice and speech. Twelve participants, >3 months post HNC treatment and experiencing some form of HNL, participated in individual, semi-structured interviews. Transcribed interviews underwent thematic analysis using an inductive approach, with subsequent member checking. Most participants felt their HNL impacted their swallowing and some had impacts on speech; although the impact on voice was less clear. Four themes emerged, including three themes relating to HNL and its impact on swallowing and speech: "it feels tight;" "it changes throughout the day;" "it requires daily self-monitoring and management;" and a fourth general theme "it affects me in other ways." Participants perceived direct impacts from HNL to swallowing and speech. They often experienced daily symptom fluctuations that required additional strategies during times of increased difficulty. Findings highlight the need to improve patient education regarding the functional impacts of HNL and the importance of self-management.

KEYWORDS
head and neck cancer, lymphoedema, qualitative research, speech, swallowing, voice

1 | INTRODUCTION

Patients who receive surgical and nonsurgical treatment for head and neck cancer (HNC) may experience widespread negative impacts to function; which may include difficulty swallowing (dysphagia), altered voice quality (dysphonia), and speech impairment (Jacobi, van der Molen, Huiskens, van Rossum, & Hilgers, 2010; Wall, Ward, Cartmill, & Hill, 2013). The nature and severity of these impacts are largely dependent upon the size and location of the tumour, the modality and intensity of the treatment, and the nature of any surgical reconstruction (Frowen & Perry, 2006; Jacobi et al., 2010). Side effects are most prevalent during the acute and subacute phases of treatment; however, many patients also continue to experience chronic side effects and may present with

progressive or late-onset dysphagia, dysphonia and speech impairment (Payakachat, Ounpraseuth, & Suen, 2013). The physiological basis for these chronic side effects has historically been attributed to the effects of definitive radiotherapy and chemo-radiotherapy, particularly the influence of tissue fibrosis and neuropathy (King, Dunlap, Tennant, & Pitts, 2016). However, there is now emerging evidence to suggest that the presence of head and neck lymphoedema (HNL) may also contribute to these chronic side effects for some patients (Deng, Murphy et al., 2013; Jackson et al., 2016; Smith & Lewin, 2010).

Head and neck lymphoedema is evidenced by the abnormal swelling and accumulation of protein-rich fluid within the interstitial spaces (Murphy, Gilbert, & Ridner, 2007), and may result from the obstruction of the lymphatic vessels, or the removal or damage of the lymphatic structures (McGarvey, Osmotherly, Hoffman, & Chiarelli, 2013). Up to 90% of patients with HNC may experience some form of HNL three months post-treatment (Ridner et al., 2016). This lymphoedema may be external (i.e., on the face or neck), internal (i.e., within the oral cavity, pharynx or larynx), or a combination of both (Deng, Ridner, Dietrich et al., 2012). HNL that does not spontaneously resolve and is left untreated, may ultimately progress and result in the development of fatty tissue deposits and contribute to the development of fibrosis (Deng, Ridner, Dietrich, Wells, & Murphy, 2013; Lewin, Hutcheson, Barringer, & Smith, 2010; Ridner et al., 2016).

Patients with HNL may experience a wide range of physical, functional and psychological symptoms. Patients have been shown to encounter altered sensation within the head and neck region causing tightness, heaviness and hardness of the skin (Deng, Ridner, Murphy, & Dietrich, 2012; Deng et al., 2015; McGarvey et al., 2013); reduced range of movement in the neck (Deng, Murphy et al., 2013; Deng et al., 2015, 2016; McGarvey et al., 2013; Tacani, 2014); difficulties with breathing (Bruns et al., 2004; Deng et al., 2016; Micke et al., 2003; Murphy & Ridner, 2010); trismus; and blurred vision (Deng, Ridner, Murphy et al., 2012; Deng et al., 2016). Patients who experience HNL are also known to experience negative effects on quality of life, body image and reduced socialisation (Brake et al., 2014; Bruns et al., 2004; Deng, Murphy et al., 2013; Deng, Ridner, Murphy et al., 2012; McGarvey et al., 2013; Micke et al., 2003; Smith et al., 2015).

In addition to these changes, preliminary evidence indicates that HNL may also negatively impact swallowing, voice and speech function (Deng, Murphy et al., 2013; Deng, Ridner, Murphy et al., 2012; Jackson et al., 2016; Piso et al., 2001; Smith et al., 2015). Deng, Ridner, Murphy et al. (2012) recently administered the Lymphoedema Symptom Intensity and Distress Survey: Head and Neck (LSIDS-H&N) to a cohort of 30 patients with HNL. Their results indicated that 53.3% reported some form of dysphagia, 56.7% reported some form of dysphonia, and 40.0% reported some form of speech imprecision and reduced intelligibility; thereby confirming the co-occurrence of dysphagia, dysphonia and speech impairment in patients with HNL. Subsequent studies, however, have demonstrated a more clear and potential causal relationship between dysphagia and dysphonia, and the presence of HNL (Deng, Murphy et al., 2013; Jackson et al., 2016). Jackson et al. (2016) showed that HNL that occurred at a number of specific internal sites was more likely to result in laryngeal penetration and aspiration, and changes in functional diet status. Whilst, Deng, Murphy et al. (2013) reported an association between the severity of HNL and increased self-reported dysphagia and dysphonia. Two qualitative studies have also noted these issues (Deng et al., 2016; McGarvey et al., 2013), with one patient commenting that "my tongue swelling, it impacted my speech… it impacted my ability to eat" (Deng et al., 2016, p. 1271). Such studies have suggested that patients may also perceive a link between their HNL and their swallowing, voice and/or speech function.

These studies have suggested that swallowing, voice and/or speech function may be influenced by the presence of HNL; however, there is currently limited information about the specific nature of these deficits and how patients perceive their HNL to influence their function. The aim of this study is to explore the experiences of patients with HNC who have HNL following treatment, and examine their perceptions of the impact of HNL on their swallowing, voice and speech function. The clinical objective of this work is to provide a greater understanding of the nature and extent of the swallowing, voice and speech issues experienced by patients with HNL in order to assist with more informed patient management.

2 | METHODS

2.1 | Research strategy

A qualitative methodology using an interpretive description approach (Thorne, Kirkham, & MacDonald-Emes, 1997) was used to explore the impact of HNL on swallowing, voice and speech function. An interpretive description approach was purposively selected as it is driven by existing knowledge, science and clinical observation (Thorne, Kirkham, & O'Flynn-Magee, 2004). Interpretive description accepts what is already known about a clinical phenomenon and thereby acts as a knowledge building process (Thorne et al., 2004). It allows for more informed questioning and interpretation, and aims to investigate specific research questions that quantitative methods are unable to adequately address (Hunt, 2009). Investigators are able to draw on their existing knowledge to capture patient's perceptions of health conditions and services; whilst also pursuing new patient experiences as they unfold (Thorne et al., 2004). This process allows for a deeper understanding of the issues in question (i.e., the impact of HNL on swallowing, voice and speech function) and also generates knowledge relevant to the clinical context.

2.2 | Sampling

Participants were prospectively recruited through the Radiation Oncology Clinic at the Calvary Mater Hospital Newcastle, Australia (1 March 2016–18 January 2017). All participants were enrolled in a

larger quantitative study examining HNL, and were considered eligible for this qualitative component if they met the following criteria: (a) they had a diagnosis of oral, nasopharyngeal, oropharyngeal, laryngeal or hypopharyngeal cancer; (b) they were a minimum of three months post definitive radiotherapy, postoperative radiotherapy, or chemo-radiotherapy; and (c) they were currently experiencing some form of HNL as determined by a transnasal laryngoscopy and head and neck examination. Participants were excluded if they: (a) were treated with palliative intent; (b) had experienced cancer recurrence within the head and neck region; (c) had undergone any surgical or laser resection involving the supraglottic or glottic larynx; (d) had pre-existing comorbidity factors that may result in HNL (e.g., trauma), or impact swallowing, voice or speech function (e.g., neurological injury or insult); or (e) were unable to provide informed consent. Participants were approached to participate in this study using a convenience sampling strategy. All participants had a former, professional relationship with the primary investigator who acted as the interviewer, due to their enrolment in the larger quantitative study. They were approached face-to-face and were aware, through the information and consent process that the interview would focus on the presence of HNL and its impact on swallowing, voice and speech function. Twelve participants were approached and all consented to be interviewed. Consent saturation was used as a criterion for discontinuing recruitment and data collection (Saunders et al., 2017); and as such, no sample size target was set (Boddy, 2016). It was noted that content saturation was reached by the tenth interview, and the final two interviews were assessed as providing no new information. Ethical approval was obtained from Hunter New England Human Ethics Committee, University of Queensland Medical Research Ethics Committee, and Calvary Mater Newcastle Research Governance Unit.

2.3 | Participant characteristics

Prior to participating in the interview process and as part of the larger quantitative study, participants underwent a transnasal laryngoscopy and head and neck examination to determine the location (i.e., external, internal or combined) and severity of their HNL. The transnasal laryngoscopy was performed by the participant's treating radiation oncologist; whilst the head and neck examination was undertaken by the primary investigator, who is a practicing speech pathologist and has undergone training in HNL assessment. The primary investigator assessed the participant's HNL with two scales. Patterson's Scale (Patterson, Hildreth, & Wilson, 2007) was used to assess the location and severity of internal HNL. This scale includes 11 laryngopharyngeal structures and two spaces; and ratings of normal, mild, moderate, or severe are applied to each structure or space. It has demonstrated moderate agreement for interrater reliability and very good agreement for intrarater reliability. The MD Anderson Cancer Centre (MDACC) Lymphoedema Rating Scale (Smith & Lewin, 2010) was used to assess external HNL. This is a five-point staging scale based on the International Society of Lymphology Rating Scale (International Society of Lymphology, 2013). It has been adapted for use in the head and neck region and allows for subtle presentations of external HNL to be captured. Additional patient demographics were also collected, including age, gender, tumour and treatment characteristics, and time post-treatment.

2.4 | Interviews

Individual, semi-structured interviews were conducted with each participant. The study authors developed an interview guide containing 10 open-ended questions, each with an example set of prompting questions, following a review of the literature (Deng, Murphy et al., 2013; Jackson et al., 2016; Smith & Lewin, 2010). Participants were asked to describe the nature and location of their HNL, any treatment they may have accessed for their HNL, and discuss any impact their HNL had on their swallowing, voice and speech function. Efforts were made to keep questions neutral in order to avoid interviewer leading and bias. For example: "tell me about your swelling" and "what do you think makes swallowing difficult?" The interview guide was trialed with a patient who had completed treatment for HNC, and who was currently experiencing HNL. Following this, the transcript was reviewed and as there were no overt difficulties or instances of patient confusion during the interview, the study authors retained the interview guide and made no further changes to the 10 questions.

Participants were given the interview guide prior to their interviews. This was undertaken to ensure that participants had the opportunity to reflect on their personal experiences, which encouraged more detailed responses (Patton, 2015). During the interviews, the 10 open-ended questions were asked to ensure the interviewer covered all aspects with each participant (Patton, 2015); whilst the prompting questions were individualised and used to seek clarification or elaboration, and explore issues raised by participants. As per participant preference, seven participants completed their interviews face-to-face in the radiation oncology clinic. Three of these had their spouses present at the time of the interview. The five remaining participants were interviewed via telephone. Participants were only interviewed once. Interviews were audio-recorded and recordings were transcribed verbatim, and checked by a second listener. The median duration of the interviews was 14 min, with a range of seven to 36 min. The participant with the shortest interview time reported minimal to no impacts to their swallowing, voice and speech function, and therefore provided minimal responses even with prompting. The primary investigator, a Caucasian, female, practicing speech pathologist, with six years clinical experience in the management of patients with HNC and HNL, completed all of the interviews. She received mentoring in interviewing for qualitative research from an experienced qualitative researcher prior to the study.

2.5 | Data analysis

Thematic analysis was conducted using an inductive analytic approach (Braun & Clarke, 2006). The investigators moved beyond

their former knowledge and conceptualisations regarding the impact of HNL on swallowing, voice and speech function, and generated new concepts and explanations regarding the specific nature of these impacts (Thorne et al., 2004). The primary investigator initially used open coding to systematically examine the data and generate initial codes (Braun & Clarke, 2006). Related codes and categories were then collated into potential themes. Constant revision of these themes was undertaken as new data was introduced. This process ensured that the themes encompassed the richness of the entire dataset, whilst also protecting against the retention of former conceptualisations (Thorne et al., 2004). Consensus coding was then conducted by two speech pathologists on 50% of the transcripts. Three of the main themes were identified by these reviewers. There were minor discrepancies surrounding the final theme, and these discrepancies were discussed until consensus was reached. This process also assisted in minimising bias. Member checking was then undertaken to verify and assess the trustworthiness of the themes (Birt, Scott, Cavers, Campbell, & Walter, 2016). Participants were sent a survey and asked to comment on the accuracy of the themes, compared with their experiences. Nine participants returned the survey and they largely agreed with the themes and examples that were proposed. Points of disagreement were minor and related to specific points raised by some participants which were not experienced by others. This was assessed as being consistent with the variability in symptom presentation and severity within the cohort. As there was no common point of disagreement, the themes were maintained and no changes were made. Finally, the number of participants who commented on each theme or category ("*n*") and the number of times each theme or category was referred to ("ref") was recorded. This process was undertaken to further demonstrate experiences that were prevalent for participants; whilst also demonstrating that there was some individual variation within this clinical population.

Within the analytic process, participant specific information regarding the presence, location and severity of their HNL was also considered. This step is nonconventional in qualitative analysis; however, some of the variability in symptom presentation and severity was able to be informed by this clinical data. This information has therefore been included to add further depth to our results and interpretation.

3 | RESULTS

Demographic and treatment details for the 12 recruited participants are summarised in Table 1. One participant refused participation in the transnasal laryngoscopy component to assess internal HNL. The mean age of the participants was 61.3 years (*SD* 6.8; range 52–72 years), and the average time post-treatment was 8.4 months (*SD* 5.1; range 3–22 months). All participants presented with a range of mild to severe external HNL; and of the 11 participants who consented to transnasal laryngoscopy, all had coexisting mild to severe internal HNL. Ten participants had received or were still receiving HNL treatment via a certified physiotherapist.

TABLE 1 Demographic, treatment and HNL data

Demographic	Parameters	Frequency (%)
Gender	Male	8 (66.7)
	Female	4 (33.3)
Primary site	Oral	5 (41.7)
	Oropharyngeal	7 (58.3)
T Stage	T 0–2	7 (58.3)
	T 3–4	5 (41.7)
N Stage	N 0–1	5 (41.7)
	N 2–3	7 (58.3)
HPV status	Positive	6 (50.0)
	Negative	6 (50.0)
Treatment	Chemo-radiotherapy	6 (50.0)
	Surgery + postoperative (chemo) radiotherapy	6 (50.0)
Neck dissection	Yes	6 (50.0)
	No	6 (50.0)
Internal HNL (*n* = 11[a])	None	0 (0.0)
	Mild	2 (18.1)
	Moderate	5 (45.5)
	Severe	4 (36.4)
External HNL (*n* = 12)	0: no visible oedema but patient reports heaviness	0 (0.0)
	1a: soft visible oedema; no pitting; reversible	4 (33.3)
	1b: soft pitting oedema; reversible	2 (16.7)
	2: firm pitting oedema; not reversible; no tissue changes	6 (50.0)

Notes. HNL: head and neck lymphoedema; HPV: human papillomavirus; N: nodal stage; T: tumour stage.
[a]One participant refused transnasal laryngoscopy, hence, internal HNL cannot be confirmed.

The prevalence of HNL and its impact on function revealed that 11 participants felt that their HNL made it harder for them to swallow, and four participants felt that their HNL specifically impacted on their speech. Ten participants also described a change in vocal quality and/or pitch. However, the majority believed that these issues were multifactorial, and the presence of xerostomia was often recognised as the main influencing factor. It was therefore difficult for participants to discuss the specific impact of HNL on their voice. For example, one participant commented that *"I get a bit of a croak… whether that's the dryness or the swelling as well… I'm not sure"* (ID 014). Due to the poor clarity regarding HNL and its relationship with

voice, analysis of data relating to voice function was discontinued. Only data relating to how HNL was felt to influence swallowing and speech was explored.

Four themes emerged from the interviews. Three of these themes specifically related to the experiences of patients with HNL and its impact on swallowing and speech. These themes included: "it feels tight;" "it changes throughout the day;" and "it requires daily self-monitoring and management." The fourth theme "it affects me in other ways" was more general and referred to comments about HNL and its impact on other functions.

The first theme "Theme 1: It feels tight" pertained to descriptions of sensory changes within the head and neck region; which were provided by all participants. This was the most salient theme to emerge from the analytic process because it was often described as a precursor to subsequent swallowing and speech issues. Two subthemes emerged which related to the perceived sensation of external HNL verses internal HNL. Eight participants described their external HNL as making the affected areas on their face and neck feel "tight" and three used similar descriptors, including "firm" and "stiff" (ref = 37): *"Just really tight around the bottom half of my chin"* (ID 056); *"It's much firmer and my skin is really tight"* (ID 024). Nine participants described altered sensation in relation to the presence of internal HNL, although these descriptions were more varied: *"Everything feels stringent or tight or rough"* (ID 014); *"Everything's closed up so much in the throat area"* (ID 030). Participants often described a change in perceived size of the pharyngeal lumen (*n* = 7; ref = 10): *"The passage way is not as big or as flexible"* (ID 031); and experiencing a change in sensation (*n* = 6; ref = 10): *"It feels like a thickening… of the inside of the throat… it doesn't feel normal"* (ID 048). Examination of participants' HNL data failed to highlight any patterns between HNL and the sensory changes that were described. Participants with a range of external and internal HNL locations and different severity levels all used very similar descriptors.

Seven participants felt that the altered sensation caused by their HNL, including tightness, stiffness and swelling had a direct impact on their swallowing (ref = 21): *"It's hard to get food to go down… because everything's closed up so much in the throat area"* (ID 030); *"Today [the food] doesn't want to move it just sits there and I feel like there must be a constriction"* (ID 024). Seven participants also reported difficulties with pharyngeal residue (ref = 20): *"You can swallow something and it can get caught in your throat… before you could probably shift it… now I have to regurgitate because with the… swelling it won't push through"* (ID 031). It was noted that participants with moderate to severe internal HNL were more likely to report these impacts, and there was no apparent difference between surgical and nonsurgical treatment groups.

Four participants also spoke of the direct impact of tightness and swelling on their speech (ref = 9): *"At times I feel my tongue is too big for my mouth and my speech is then very slurred and much worse than what it is now… very difficult to understand"* (ID 024); *"I'm not talking normal because of the swelling of the tongue"* (ID 034). These four participants had all undergone a hemiglossectomy and free flap repair with postoperative radiotherapy. They were all experiencing lingual lymphoedema; in addition to the anatomical changes associated with their surgery and reconstruction/repair.

The second theme "Theme 2: It changes throughout the day" pertained to comments relating to temporal changes in HNL and its associated impacts to swallowing and speech function. Eight participants specifically spoke of temporal changes (ref = 23), noting that their HNL was worse in the morning and often subsided throughout the day. The key pattern surrounded the building or increasing intensity of their HNL symptoms overnight: *"It's mainly there first thing in the morning… it's a build up overnight"* (ID 030); *"As the day goes on it sort of goes down… but it seems to always come up during the night"* (ID 017). In contrast, a small number of participants felt that their HNL was fairly constant (*n* = 3; ref = 3) and they did not experience any temporal changes. These participants all had firm pitting external HNL, whereas the vast majority of participants reporting temporal changes had soft external HNL with no pitting. Two of these participants also described long-term changes in their tissues, as opposed to daily fluctuations. These participants spoke of the progression from soft to firm pitting external HNL (ref = 4): *"It was always a lot softer… now it's a lot harder"* (ID 056); *"The swelling hardened after radiotherapy"* (ID 034).

Five participants spoke of the specific impact of these temporal changes on their swallowing (ref = 10): *"It changes throughout the day… it will be fine then all of a sudden I notice it's a little bit harder to swallow… generally if it's going to happen it's in the morning"* (ID 024); *"Each day is different… some days things might go down easy… but the next day everything feels stringent or tight or rough… you know on the inside… then it's hard to get anything down on those days"* (ID 014). One participant also described the impact of temporal changes within their HNL on their speech: *"At times I feel like my tongue is too big for my mouth and my speech then is very slurred and much worse than what it is now… very difficult to understand… my tongue probably is swollen"* (ID 024).

The third theme "Theme 3: It requires daily self-monitoring and management" related to the strategies that participants used to manage their HNL and its associated impacts to swallowing and speech function. All participants stated that they were undertaking some form of daily home management for their HNL (ref = 46); such as massage, the use of compression garments, or sleeping in supported positions: *"I was shown how to massage my face and neck to help the lymph nodes relieve the fluid"* (ID 031); *"They had an elasticised bandage that they put on… to try and hold pressure on it through the night"* (ID 030); *"I try to elevate myself… I sleep in a different way so that I'm moving my head in different positions"* (ID 030). However, the dominant comments pertained to the use of self-administered daily massage (*n* = 11; ref = 30); which many participants completed first thing in the morning to minimise the fluid that had accumulated overnight: *"I give it a massage early in the morning… the massage makes the swelling feel better"* (ID 008). Some participants also stressed the importance of movement and positioning in the morning to relieve their symptoms (*n* = 4; ref = 13): *"I did get up and walk around… it dispersed the fluid build-up that was there. Even if I just sat right up in bed it would help disperse the fluid"* (ID 030).

Nine participants also spoke of additional management strategies for when their HNL was impacting their swallowing (ref = 34). Two participants described using a hot drink in the morning to help get their swallow "going" each day (ref = 2): *"It's hardest [in the morning] until I've had a cup of tea or something to soothe it a little bit and get all the muscles working. It's quite hard to get everything going in there"* (ID 014). Most participants also spoke of implementing additional compensatory strategies, such as increased diet modification, cutting up food finely, and regular fluid washes (*n* = 9; ref = 32): *"I persevere… I drink a bit more water… and I take a lot longer… I tend to cut [the food] a lot finer… it's usually only when I've got the… swelling"* (ID 040); *"You have to try and have a drink to wash it down or have more food… when you swallow that hopefully it pushes the first lot down and not chokes you"* (ID 030). Two participants also spoke of the need to modify their speech to adjust to their impacted articulatory function (ref = 3): *"Because of the swelling of the tongue and… under the chin… I [have] to talk slower"* (ID 034). Nine participants discussed their acceptance of their changed function, and highlighted that this was an important part of learning to adapt and being able to cope with change (ref = 11): *"You just learn a new means and you just get on with it"* (ID 030).

The fourth and final theme to emerge from the interviews "Theme 4: It affects me in other ways" reflected the comments made in relation to HNL and its more widespread impact on patient function. Whilst the interview focused on HNL and its associated impact on swallowing, voice and speech function, during the course of the interview, 11 participants also described other impacts that they felt their HNL had upon them. The vast majority of participants spoke of the impact of HNL on their emotional wellbeing (*n* = 11; ref = 27). Some participants specifically highlighted the negative impact of external HNL on body image (*n* = 5; ref = 9): *"I try to cover it up when I go out… so that people don't look at me… [I feel] very self-conscious. That's why I wear high collared shirts most days"* (ID 034). All of the female participants spoke of issues with body image, whilst, the vast majority of male participants stated that they had learnt to adjust and they did not let their HNL bother them: *"It's never really bothered me as much mentally… because I'm used to it… I can live with it"* (ID 042). Other participants also felt frustration surrounding their HNL and the slow rate of improvement (*n* = 3; ref = 7): *"I'd like for it to be over… I wish there was a pill you could take… to get rid of it"* (ID 046); *"They have told me it will take time… that's where I reckon… the frustration comes into it… because you do everything you are told to… you don't believe you are getting anywhere"* (ID 034). Whilst others spoke of consciously needing to adjust to their HNL (*n* = 9; ref = 11); which was previously detailed.

In addition to the impacts on emotional wellbeing, participants also discussed other functional impacts of their HNL. Many felt that their HNL impacted on their ability to sleep (*n* = 5; ref = 7); with some reporting that it caused them to wake during the night. This was often attributed to feelings of heaviness, bulkiness, and stiffness of the neck: *"I wake up numerous times throughout the night now where I never used to… when I wake up [the HNL] does feel heavy"* (ID 048). A few participants also complained of difficulty breathing when lying flat on their back during sleep (*n* = 3; ref = 7), which they again often attributed to feelings of heaviness and tightness on the external neck: *"I got out of bed one night because I thought I was going to die. I just couldn't get air in whatsoever"* (ID 030). Finally, some participants described feelings of increased sensitivity at the site of their external HNL and spoke of associated discomfort (*n* = 5; ref = 25): *"There are times when the [HNL] gets quite painful, well not painful… uncomfortable"* (ID 024); *"Everything is super sensitive"* (ID 030).

4 | DISCUSSION

Recent quantitative studies have begun to establish the relationship between the presence of HNL and its impact to swallowing, voice and speech function (Deng, Murphy et al., 2013; Deng, Ridner, Murphy et al., 2012; Jackson et al., 2016; Piso et al., 2001; Smith et al., 2015). However, the specific nature of these impacts from a patient perspective has not been previously presented. The current study has revealed that many participants perceived their HNL to directly impact their swallowing, whilst some also experienced impacts to speech function. The impact of HNL on voice was unable to be determined as most participants believed their voice was impacted by multiple factors, such as xerostomia and secretions, and not isolated to HNL alone. This study offers insights into the nature of the impacts to swallowing and speech, and offers valuable information for clinicians managing patients who experience HNL.

All participants had some degree of external and/or internal HNL which co-occurred with reports of altered sensation within the head and neck region. Feelings of tightness, heaviness and feeling swollen on the external face and neck were highlighted, which is consistent with previous research (Deng, Ridner, Murphy et al., 2012; Deng et al., 2015; McGarvey et al., 2013). The vast majority also described altered sensation in relation to the presence of internal HNL, which has also been previously documented (Deng et al., 2016). The presence of altered sensation is often one of the first symptoms described by patients with HNL (Smith & Lewin, 2010). Deng et al. (2015) found that there was a high occurrence of these symptoms in patients with HNL, compared to patients without HNL. Hence the concept of altered sensation has important clinical implications. Attention to these patient-reported symptoms may allow clinicians to screen, diagnose and treat new or emerging HNL in a timely manner.

The vast majority of participants felt that that their HNL had altered their swallow function; which many attributed to the feeling of tightness and swelling within their pharynx. Multiple authors have suggested an association between HNL and increased issues with swallowing (Deng, Murphy et al., 2013; Deng et al., 2016; Jackson et al., 2016; Murphy & Gilbert, 2009; Murphy & Ridner, 2010; Murphy et al., 2007; Piso et al., 2001; Smith et al., 2015). Internal HNL has the potential to cause significant thickening and stiffness of the pharyngeal and laryngeal structures; thereby affecting their range of movement and contractibility (Eisbruch et al., 2004; Jackson et al., 2016; Murphy et al., 2007). This may result in

prolonged pharyngeal transit time, reduced pharyngeal clearance, and laryngeal penetration and aspiration (Deng, Murphy et al., 2013; Jackson et al., 2016). Data from the current study suggest that HNL causes noticeable changes in oropharyngeal swallow for some patients. However, it is also recognised that there also be other influencing factors, such as xerostomia, secretions, and/or fibrosis.

Whilst swallowing changes were reported by the vast majority of participants, only a small number felt that their internal HNL impacted on their speech function. This finding may be reflective of the small number of participants treated with postoperative radiotherapy; as anecdotal evidence suggests that this patient group is at highest risk of experiencing impacts to speech, likely due to both surgical and radiotherapy effects. Participants who reported speech changes felt that swelling of their tongue impacted on their ability to speak clearly and be understood by others. These findings offer support for the notion that HNL in the oral cavity may further impair the functioning of the structures used in articulation (Lewin et al., 2010). The findings are also consistent with a small number of studies that have noted patient-reported speech imprecision and unintelligibility in patients who experience HNL (Deng, Ridner, Murphy et al., 2012; Deng et al., 2016; Piso et al., 2001).

Multiple participants discussed temporal changes in their HNL and corresponding fluctuations to their swallowing and speech function throughout the day. Many stated that they had to monitor their swallowing and implement additional compensatory strategies when temporal changes occurred. One participant also noted temporal changes in their speech function. This pattern of temporal change was more often described by those patients with soft and nonpitting external HNL, rather than firm and pitting external HNL. It is known that temporal changes in HNL exist and that swelling often increases overnight (Deng et al., 2016; McGarvey et al., 2013); likely due to positioning and the negative effects of gravity during sleep, which may lead to an accumulation of lymph fluid. However, this is the first study to document temporal changes specifically within swallowing and speech function, and highlight the subgroup of patients most likely affected. There is a need for clinicians to be aware that patients who experience HNL may encounter temporal changes and that their swallowing and speech function may fluctuate throughout the day.

Due to the impact of HNL and its associated temporal changes, the need for daily self-monitoring and management was noted to be vitally important by participants. All were completing some form of daily home management for their external HNL, in an effort to relieve their symptoms. This finding is consistent with prior studies which have reported high rates of self-management within this patient population (Deng & Murphy, 2016; Smith et al., 2015). Participants also stressed the importance of monitoring their swallowing and speech function and implementing compensatory strategies accordingly; such as diet modification, additional fluid washes, and clear speech strategies. These findings reinforce the need for speech pathologists to prepare these patients with contingency plans and appropriate compensatory strategies for when they encounter increased difficulties at mealtimes and in their speech due to fluctuating HNL effects.

The vast majority of participants also discussed other ways in which their HNL had altered their life and function; including their emotional wellbeing, sleeping and breathing. Many functional and psychosocial impacts have been associated with HNL (Deng, Murphy et al., 2013; McGarvey et al., 2013; Murphy & Ridner, 2010; Smith et al., 2015); and the desire for the current participants to discuss these during their interviews, highlights the widespread impact HNL can cause to patient function. It also reinforces the need for a multidisciplinary team approach to patient management in order to support patients in minimising all of the associated impacts and optimise their quality of life.

4.1 | Limitations

Despite the utilisation of a convenience sampling strategy, the participant sample is diverse. It includes participants treated with both surgical and nonsurgical treatments, participants at a variety of time-points post-treatment, those with both external and internal HNL, and those with different HNL severity levels. However, this diversity may also be a limitation of the study. Future research that limits the participant sample to those with similar treatment and HNL variables may provide different insights into the impact of HNL on swallowing and speech function. This study also made no attempt to separate the early and late impacts of HNL, and all participants were recruited from the same service. Future research that explored the trajectory of HNL and its impacts would be valuable. Recruitment from a number of different services may also highlight differing patient perceptions and ideas on support. Furthermore, it is recognised that patients with a diagnosis of nasopharyngeal, laryngeal and hypopharyngeal cancer are not represented in this study, which may also be seen as a limitation.

This study also intended to examine the impact of HNL on voice function. However, whilst most participants reported a change in their vocal quality and/or pitch following treatment, they believed that these issues were multifactorial and the impact of HNL alone was unable to be determined.

5 | CONCLUSIONS

Many participants within this cohort felt that their HNL had a negative impact on their swallowing and speech function. Insights from their experiences reveal that the presence of HNL may have contributed to increased difficulty swallowing, had negative effects on bolus flow, and also had an impact on the speed and precision of their articulatory movements for speech. These functional changes often fluctuate with HNL symptoms, and therefore require patients to monitor their function on a daily basis and implement compensatory strategies as required; such as diet modification, additional fluid washes, and clear speech strategies. Speech pathologists need to be aware of and monitor their patients for HNL and any associated

impacts on swallowing and speech function, and ensure they prepare patients with contingency plans to manage times of increased difficulty. The multidisciplinary team also need to remain aware of the widespread impacts of HNL, including swallowing and speech changes, so that symptom management and supports are provided in a timely manner for all patients.

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CONFLICT OF INTEREST

The authors report no conflict of interests. The authors alone are responsible for the content and writing of the manuscript.

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