

## **Communication changes following non-glottic head and neck cancer management: The perspectives of survivors and carers**

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### **Abstract**

**Purpose:** Head and neck cancer (HNC) survivors may experience functional changes to their voice, speech, and hearing following curative chemoradiotherapy. However, few studies have explored the impact of living with such changes from the perspective of the HNC survivor and their carer. The current study employed a person-centered approach to explore the lived experience of communication changes following chemoradiotherapy treatment for HNC from the perspective of survivors and carers.

**Method:** Participants included 14 survivors with non-glottic HNC and 9 of their carers. All participants took part in in-depth interviews where they were encouraged to describe their experiences of living with, and adjusting to, communication changes following treatment. Interviews were analysed as a single data set.

**Results:** Four themes emerged including: (1) impairments in communication subsystems; (2) the challenges of communicating in everyday life; (3) broad ranging effects of communication changes; and (4) adaptations as a result of communication changes.

**Conclusion:** These data confirm that communication changes following chemoradiotherapy have potentially negative psychosocial impacts on both the HNC survivor and their carer. Clinicians should consider the impact of communication changes on the life of the HNC survivor and their carer, and provide adequate and timely education and management to address the needs of this population.

## **Introduction**

As the seventh most common cancer worldwide, head and neck cancer (HNC) contributes considerably to the global cancer burden, with approximately 686,000 new cases identified in 2012 (Ferlay et al., 2014). Due to the advances in the detection and treatment of HNC, the ageing population, and the recent surge in human papillomavirus (HPV) mediated tumours (D'Souza et al., 2007; Gillison & Lowy, 2004; Vidal & Gillison, 2008), this number is expected to increase by 35% by the year 2025 (Ferlay et al., 2014). In contrast to the traditional profile of an individual with HNC (i.e. adults in their sixth or seventh decade of life, and strongly associated with tobacco and alcohol), commonly individuals with HPV-positive oropharyngeal tumours are middle-aged men, often with higher socioeconomic status, who consume nil or limited amounts of tobacco or alcohol (D'Souza, Zhang, D'Souza, Meyer, & Gillison, 2010; Gillison et al., 2008). These factors all contribute to an increasing number of younger people living long-term with the significant functional sequelae associated with curative HNC treatment (Pulte & Brenner, 2010). Though cure remains of primary importance, in recent years there has been an increasing interest in the functional outcomes of non-surgical treatment.

Changes to swallowing, nutrition, and quality of life function have been widely reported functional deficits in survivors of HNC following chemoradiotherapy, with changes to voice, speech, and hearing less frequently discussed in the literature. A recent systematic review of speech and voice outcomes following chemoradiotherapy identified just 20 relevant studies from the last two decades (Jacobi, van der Molen, Huiskens, van Rossum, & Hilgers, 2010). This body of research supports that voice and speech functions degenerate during the course of chemoradiotherapy, with subsequent improvements occurring 1-2 months post-

treatment, and exceeding pre-treatment levels by 12 months (Jacobi et al., 2010). Yet despite this pattern of post-treatment ‘recovery’, voice and speech function are typically noted to fall outside the normal range at all time points: before, during, and following treatment (Jacobi et al., 2010).

In most existing studies of voice and speech outcomes following HNC management, the primary study population has been HNC survivors with glottic tumors, due to the obvious causal relationship between tumor presence and direct treatment effects to the larynx such as reduced vocal fold mobility impacting on pitch and volume range (Lazarus, 2009). Other commonly reported sequelae of chemoradiotherapy for HNC, which may impact on the communication subsystems, include: xerostomia (chronic salivary gland dysfunction) affecting the lubrication and hydration of the vocal folds (Lazarus, 2009; Roh, Kim, & Kim, 2006) and the speed, sequencing, and accuracy of speech sound articulation (Epstein & Stevenson-Moore, 2001); dental extraction of suspect teeth prior treatment due to the effects of radiotherapy on normal mucosal healing (Koga, Salvajoli, & Alves, 2008); and sensorineural hearing impairment as a result of ototoxic chemotherapy drugs (Low, Toh, Wee, Fook-Chong, & Wang, 2008; Zuur et al., 2007). These secondary sequelae are also common following chemoradiotherapy for non-glottic tumours. Further to this, though these individuals do not have a tumour in the laryngeal region, the advent of new conformal radiotherapy techniques such as intensity modulated radiotherapy (IMRT) and volumetric modulated arc therapy (VMAT) means that low doses to the larynx are still possible and may continue to affect vocal fold function despite treatment being focused away from the larynx (Sanguineti, Ricchetti, McNutt, Wu, & Fiorino, 2014).

At present however, relatively little is known about voice and speech outcomes following treatment for non-glottic cancers (Fung et al., 2001; Hamdan et al., 2009; Paleri et

al., 2012). In the only known prospective study of voice outcomes following non-surgical management in non-glottic HNC, chemoradiotherapy was shown to have a significant effect on HNC survivors' self-reported vocal function, as rated on the Voice Symptom Scale (VoiSS; Deary, Wilson, Carding, & MacKenzie, 2003), up to 12 months post-treatment (Paleri et al., 2012). However, whilst clinician-rated acoustic and perceptual measures of voice function deteriorated early post-treatment, improvements were noted at 12 months post-treatment, though not to pre-treatment levels (Paleri et al., 2012).

In a heterogeneous group of HNC survivors, van der Molen et al. (2012) found that HNC survivors' perceptions of their vocal function only weakly correlated with expert judgment, as there was a mismatch between the clinician-rated and patient-reported outcomes of voice pre-radiotherapy, 10 weeks post-radiotherapy, and 1 year post-radiotherapy. More recently, Lazarus et al. (2014) noted that HNC survivors' reported impaired speech, as measured by the Speech Handicap Index (Rinkel, Verdonck-de Leeuw, van Reij, Aaronson, & Leemans, 2008), following chemoradiotherapy. This was in contrast to clinician-perceptions of complete intelligibility, both before chemoradiotherapy treatment, and at 3 and 6 months post-treatment. These inconsistencies between objective ratings of voice and speech versus patient-reported ratings highlight the need to explore any changes in communication from the HNC survivors' perspectives. It also highlights the limitations of impairment-based measures which may not accurately capture survivor perceptions of their communicative function, and the associated impact on their daily life. There is a need for research methods to adopt a more holistic patient-centred approach which stresses the importance of understanding the everyday experiences of the individual with the health condition in their terms (Barry & Edgman-Levitan, 2012; Robinson, Callister, Berry, & Dearing, 2008).

Qualitative research provides greater capacity to explore HNC survivors' perspectives of communication changes following HNC treatment. In a recent study, Swore Fletcher, Cohen, Schumacher, and Lydiatt (2012) used qualitative methods to explore the perspectives of 39 HNC survivors between 2-24 months post-treatment regarding their experiences of communication during and after HNC treatment. Two major themes were identified: 'going deeper into life' and 'change in communication', where the latter encompassed changes to functional communication in everyday life, such as social isolation, difficulty adapting to the changes, and effortful communication (Swore Fletcher et al., 2012). To compensate for changes in communication, participants in this study made numerous adaptations, such as reducing speaking rate, word substitutions, over articulation, and increasing volume (Swore-Fletcher et al., 2012). These strategies reflected the level of effort required to communicate, highlighting the impact of these changes on daily life. Though this was the first study to provide insight into the challenges associated with living with communication changes following HNC management, the authors provided limited information on the participant population in terms of tumour site and type of treatment received. Therefore, the extent to which these results are reflective of the experiences of HNC survivors with non-glottic tumours who have received curative chemoradiotherapy cannot be determined from the data presented.

Though further research is needed to understand the experiences of HNC survivors living with communication changes, survivors are not the only stakeholders affected by communication changes. Carers are important members of a cancer survivor's support team, providing valuable practical and emotional support before, during, and following treatment (Girgis & Lambert, 2009). Given that communication is a two-way process, it is also likely that any changes to the HNC survivors' communicative abilities will also impact on the life of their carer. To date, there has been a paucity of research regarding the experiences of

carers living with, and supporting, HNC survivors with communication changes. As a result, there is a limited amount of evidence available to researchers, clinicians, and policy makers regarding the support needs of carers of HNC survivors. Therefore, a deeper understanding of their experiences and support needs is required.

As such the aims of this study were to explore the views and experiences of communication changes following curative chemoradiotherapy for non-glottic HNC from the perspective of both the HNC survivor and their carer. This study seeks to understand the challenges faced by both HNC survivors and carers in regards to communication changes, and elucidate the skills needed and support required, to adjust to these communication changes following treatment. This study forms part of a larger project exploring mealtime and communication difficulties in HNC survivors and their carers.

## **Methods**

A qualitative descriptive research design was utilised to comprehensively explore the experiences of HNC survivors' and their carers regarding any communication changes experienced following curative non-surgical treatment for HNC (Sandelowski, 2000). Due to the subjective, individual, and exploratory nature of the research questions, a phenomenological stance was adopted. Phenomenology allows the researcher to elucidate the meaning and experience of everyday existence from the perspective of the individual (Patton, 2002).

## **Sampling**

Due to the heterogeneous nature of HNC and its treatment, participants were recruited using maximum variation sampling, ensuring that all participants varied demographically from one another (Patton, 2002). In maximum variation sampling, any common patterns to emerge

from the data are considered to be particularly interesting as they capture the core and central shared experiences of a particular population (Patton, 2002). The variables used to achieve variation in the HNC survivor sample included: gender (male/female); age (<65 years/ $\geq$ 65 years); geographic location (major city/regional and remote); and months since treatment (<3 months/ $\geq$ 3 months). Similarly, carer participants were selected on the basis of: gender (male/female); month since partner's treatment (<3 months/ $\geq$  3 months); and employment status (paid employment/not in paid employment). To ensure the studies criteria for maximum variation sampling was met, at least one participant was selected in each category.

## **Participants**

### **Head and neck cancer survivors.**

The first participant group included 14 individuals (12 male, 2 female; age range = 43-67 years,  $M = 56.1$ ,  $SD = 7.8$ ) who had completed curative chemoradiotherapy for a non-glottic HNC at a tertiary hospital in Brisbane, Australia, between April 2007 and April 2012.

Participants were excluded from the study if they: (a) had received primary surgical management; (b) had pre-existing conditions associated with communication impairments (e.g. neurological conditions, moderate-severe cognitive impairments, degenerative conditions, hearing impairment); (c) were considered palliative; and/or (d) were not proficient in English. HNC survivor participants presented with nasopharyngeal, oropharyngeal, and hypopharyngeal primaries. All participants had self-reported changes to their communication during and/or following treatment. The majority of participants had completed their treatment more than three months prior to being interviewed with a mean of 17.1 months post-treatment ( $SD = 15.1$  months, range = 1.5-46 months).

### **Carer participants.**



The carer participants recruited in this study included nine partners (eight females, one male) of non-glottic HNC survivors who had undergone curative non-surgical treatment. Carer participants were also excluded if: (a) they had previously or were currently undergoing treatment for HNC; (b) had pre-existing conditions associated with communication impairments (e.g. neurological conditions, moderate-severe cognitive impairments, degenerative conditions, hearing impairment); (c) were not proficient in English; and/or (d) if their partner with communication changes had been excluded for the aforementioned reasons. The carer participants ranged in age from 45 to 60 years, with a mean of 52.4 (SD = 5.05). Carer participants were either in a defacto relationship or were married to an individual with non-glottic HNC, with a range in relationship length from 5 to 43 years (M = 23.4; SD = 11.6). HNC survivor and carer participant details with maximum variation sampling parameters and additional demographic details are reported in Table 1.

[Insert Table 1 near here]

Please note all of the HNC survivors and seven carers within this study were involved in the larger project surrounding mealtime difficulties that may arise from HNC and its treatment which have been published elsewhere (Nund et al., 2014a, b, c).

## **Procedure**

Both HNC survivor and carer participants took part in semi-structured, individual, in-depth interviews with the principal investigator. Prior to their interviews, each participant was sent a list of stimulus questions to encourage personal reflection in preparation for their interview (Patton, 2002). An interview guide was utilised to ensure all relevant topics were covered and to allow for open-ended discussion, however questions were adapted, omitted, or elaborated depending on the individual participant to ensure a conversational style interview was maintained (Patton, 2002). HNC survivor participants were encouraged to speak freely and

comment on any communication changes they had experienced following their treatment and its associated impact on their life. Similarly, carer participants were encouraged to speak openly about the effects of their partner's communication changes on their life. Interviews ranged in duration from 20 minutes to 2 hours. Each interview was audio-recorded and transcribed verbatim for analysis. Ethical clearance for this study was obtained from the relevant human research ethics committees and each participant provided written informed consent.

### **Data Analysis**

The interview transcripts from both participant groups were analysed together using thematic analysis, following the steps outlined by Braun and Clarke (2006). An inductive approach was used to identify patterns within the data as a whole, ensuring that themes were sourced directly from the interviews (Braun & Clarke, 2006; Patton, 2002). Meanings and patterns were identified through thorough reading of the interview transcripts, and open coding was used to identify statements relating to participants' experiences of communication changes (Strauss & Corbin, 1998). Coding was performed with the assistance of the NVivo10 software program. A list of categories was developed from the codes and further refined by co-investigators until consensus was established. All interview transcripts were subsequently recoded using the revised list of categories. Themes were developed by considering the potential relationships between categories (Braun & Clarke, 2006). The themes were reviewed in relation to each original transcript to note the extent to which each theme was representative across the data set. To ensure that rigor and consensus were maintained, the co-investigators reviewed the codes, categories, and themes at regular research meetings.

### **Results**

Four overarching themes emerged from the interviews, which captured the experiences of living with, and adjusting to, communication changes following non-surgical HNC management. The first of these themes, impairments in communication subsystems, was unique to the HNC survivors group. The remaining three themes, including the challenges of communicating in everyday life, broad ranging effects of communication changes, and adaptations as a result of communication changes reflected common issues and concerns raised from the perspectives of both HNC survivors and carers.

### **Theme 1: Impairments in communication sub-systems**

HNC survivors spoke often of the physical changes resulting from treatment which had impact on their communicative abilities (Table 2). Many described experiencing changes to their voice for months and years following treatment. In particular, functional loss was noted in conversational exchanges *‘[I need] to use so much more energy to be able to get the voice out.’ [P009]* Sometimes this led to the communicative intent being misinterpreted as aggression: *‘The response will come back “stop yelling”. I’ll say “I’m not yelling, I have to use this voice so that you can hear me.”’ [P009]* Additionally, some participants reported pitch changes, hoarseness, vocal fatigue, a feeling of something in the throat, and that their voice was often worse first thing in the morning. For half the participants, xerostomia (dry-mouth) had a substantial impact on everyday communication: *‘The dry mouth. It affects everything. It affects your throat, it affects your mouth, eating, swallowing, talking ... everything, it affects everything.’ [P009]* A few participants also spoke about the negative impacts of chemoradiotherapy-induced hearing impairment following treatment: *‘I’ve gone partly deaf and that is what makes it hard. I can’t hear what’s going on. I don’t know what’s going on.’ [P016]*

[Insert Table 2 near here]

## Theme 2: The challenges of communicating in everyday life

Both HNC survivors and carer participants discussed a number of challenges they faced regarding communicating in everyday life (Table 3). This theme was particularly relevant for the HNC survivors who had experienced hearing impairment as a result of their treatment. The most frequently reported challenge was the lack of understanding from others about their communication changes: *'The biggest challenge is getting other people to adapt to your hearing. You get a bit offended from time to time when they won't bother to talk to you because they think you can't hear.'* [P012] As a result of this lack of understanding, this participant noted that *'you feel as if you're left out quite often because people get frustrated and rather than say something to you they don't bother.'* [P012]

Another frequent challenge, particularly for the HNC survivors with hearing impairment, was *'the background noise, when that's happening it is a lot harder for me.'* [P019] Finally, both HNC survivors and carers faced challenges regarding support for communication during treatment from health professionals such as speech-language pathologists: *'they were very good, but it [the sessions] was really not to do with communication, it was really to do with being able to swallow and what sorts of food I could eat. That was frustrating for me.'* [P009] One of the carer participants summed up her experience by stating: *'I don't really think there's a lot of support there for carers.'* [C002] The majority of participants felt that the information provided by health professionals needs to be delivered in lay terms, and include a discussion of the implications of the side effects of treatment on their life: *'The explanations before treatment ...like hearing [impairment], sore throat or may not produce saliva ....was put in a medical way but the reality is the human element of it and the [life] effects, no one tells you about that.'* [C016]

[Insert Table 3 near here]

### Theme 3: Broad ranging effects of communication changes

The physical changes to the communication sub-systems as a result of treatment, coupled with the challenges of communication in everyday life, resulted in broad ranging effects on communication interactions for both the HNC survivors and their carers (Table 4). The most dominant category was the impact of the communication changes on family life, particularly in regards to family relationships and roles and responsibilities within the family unit. One HNC survivor noted that: *'My children tend to talk to my wife more now. I miss out on bits of information.'* [P012] Conversely, one of the carer participants commented that: *'He doesn't like to read with [our daughter] anymore because he lisps a lot if he hasn't got his teeth in properly.'* [C002] These impacts were not confined to the family unit alone, and both groups of participants commented on the impact of the communication changes on their social lives, as noted by this HNC survivor: *'You might not go out as often as you should. It's just much easier not to have to communicate.'* [P012] Similarly, one of the carer participants stated that during treatment and in the acute recovery period that *'it was a bit like life was on hold, we didn't go out, we didn't visit people and he preferred they didn't visit us.'* [C005] For the HNC survivors, the impact also extended into their work life: *'I load trucks and I sent 20 tonnes of the wrong steel to Sydney because I couldn't hear well. They [work] weren't impressed.'* [P016]

As a result of these impacts, both the HNC survivors and the carers spoke about their emotional response to the communication changes including frustration and embarrassment for HNC survivors: *'With communication it's mainly [the] embarrassment. I've been [involved] in this [community organisation]. I'm seriously thinking of quitting because of [my communication changes]'* [P011], and frustration, concern, and sadness for carers. Despite these broad ranging effects, some HNC survivors and carers spoke about how they

had not let the communication changes become a barrier: *'it doesn't stop you from talking, it might just slow me down for a couple of minutes.'* [P008]

[Insert Table 4 near here]

#### **Theme 4: Adaptations as a result of communication changes**

The fourth theme to emerge from the interviews related to the comments made by both HNC survivors and carers regarding the necessary adaptations required to adjust and cope with the communication changes (Table 5). To facilitate successful communication interactions and adapt to changes in their communication, the HNC survivors used a number of practical strategies to compensate for the changes such as ensuring they always carried a bottle of water *'to be able to talk to people.'* [P009] A couple of HNC survivors also discussed the use of chewing gum, artificial saliva, and oral sprays to increase moisture in the mouth.

In order to adapt to the changes to hearing, HNC survivors discussed a number of strategies including moving closer to their communication partner, asking them to speak louder, and confirming the message to ensure what they heard was correct. Survivors who experienced voice changes improved their communication by performing vocal hygiene strategies such as drinking hot water with honey, using steam, and in the case of a professional voice user, ensuring she completed a proper warm up before performing. They also discussed other strategies such as avoiding communication interactions if possible, using non-verbal communication such as lip reading, and exploring the use of different technologies such as earphones for the television and hearing aids. Carer participants reported using similar strategies to the HNC survivors, such as encouraging their partner to drink water to relieve their dry mouth, answering the phone for their partner so that they didn't have to talk, repeating themselves to ensure their partner had received the correct message, pursuing Auslan classes to learn sign language, and conducting their own research into

technology that could assist with communication changes. Some HNC survivors and carers reported participating in regular sessions with a speech-language pathologist and dietitian. However, these interactions when discussed by participants were focused on mealtime difficulties and not the management of their communication changes.

Emotional adaptation was also paramount to adjusting to the changes to communication for both survivors and carers. A number noted that *'it's just an acceptance thing'* [P019] and that the change *'is what it is ... you just deal with it.'* [P019] Others remained hopeful that their communicative function (or their partner's communicative function) would one day return to normal. Finally, HNC survivors and carers both discussed the importance of support from their family and friends, as well as from other HNC survivors and carers as part of their adjustment to communication changes.

[Insert Table 5 near here]

## Discussion

This study has provided an in-depth description of the experiences of living with, and adapting to, communication changes following chemoradiotherapy management for non-glottic HNC from the perspective of the survivor and their carer. This unique perspective highlights the multifactorial and pervasive nature of communication changes following non-surgical management, beyond the physiological changes to speech, voice, and hearing. Both survivors and carers reported negative impacts across a number of life areas, including their family and social lives. In response to these changes, participants described a number of adaptations required to adjust and live successfully with communication changes. Overall, these data demonstrate the widespread nature of communication changes, which underpin a number of life areas, and highlight that both HNC survivors and their carers are in need of supportive services to assist with coping and adjustment during and following treatment.

Consistent with previous research, the HNC survivors in the current study reported ongoing changes to their speech, voice, and hearing which persisted for months and years post-treatment (Lazarus et al., 2014; Paleri et al., 2012; Swore Fletcher et al., 2012). Though these changes to the communication sub-systems did actually not preclude them from communicating and socialising, the changes made communicating more difficult. It should also be noted that the physical sequelae of chemoradiotherapy (including xerostomia, hearing impairment, voice changes, dental extraction) were interrelated and the resultant communication changes were heightened by the multifactorial origins. These changes, coupled with the challenges to communicating in everyday life, led to negative effects on family, work, and social lives. These findings highlight the importance of moving beyond impairment based measures of voice, speech, and hearing, to include more holistic assessments of communication participation.

Communication participation emphasises the importance of taking part in life situations in which knowledge, information, ideas or feelings are exchanged. It is specifically concerned with communication that occurs in the various life situations in which people take part. A new tool, The Communicative Participation Item Bank (CPIB; Baylor, Yorkston, Eadie, Miller & Amtmann, 2009), has been developed to measure to extent to which an individual's condition interferes with their participation across a range of speaking situations. It has been suggested that the CPIB could be adopted by health professionals working the HNC population to assess communication outcomes following treatment (Eadie et al., 2014). Adopting the routine use of such tools in order to detect the broader implications of communication changes may assist clinicians to identify those individuals who require additional education, training, and support to adjust to their communication changes. This tool requires further clinical validation to determine whether its use is feasible in everyday



clinical contexts. It is unknown whether the 10-item disorder short form (Baylor et al., 2013) could be utilized.

The current data has also highlighted that the impacts of communication changes following HNC are not confined to the HNC survivor, but also impact on the life of the carer. Carers reported that the communication changes of their partner had a negative effect on their family and social lives. To the authors' knowledge, this is the first known study to report on the effects of communication changes on the carer following HNC management. Using the World Health Organization's (WHO) International Classification of Functioning, Disability and Health framework (2001) the effects of a health condition on the functioning of carers has been termed 'third-party disability'. Third-party disability has received growing attention in other client populations affected by communication disability, including spouses of older adults with hearing impairment (Scarinci, Worrall, & Hickson, 2009) and in close family members of people with aphasia (Grawburg, Howe, Worrall, & Scarinci, 2013). Given that direct associations have been found between carers' psychological health and patient outcomes in other health states, including dementia (Lang et al., 2010) and lung cancer (Porter et al., 2011), the consideration of the carers' psychological health and coping abilities may be an important consideration for health professionals. Taken together, this provides the impetus for future research in third-party disability in carers of HNC survivors with communication changes and what is needed in terms of interventions for this group.

In order to cope with, and adjust to, the broad ranging effects of communication changes including the physical, emotional, and lifestyle changes, both survivors and carers in this study described a number of strategies they had adopted. These adjustments were made (largely) without the support of health professionals. This is consistent with the findings of Swore Fletcher et al. (2012) who noted that participants in their study had often developed

their own strategies in order to adjust to their communication changes. These findings support the need for health professionals within the multidisciplinary team to review the provision of services relating to communication rehabilitation in order to better assist both HNC survivors and carers to adjust to these changes during and following HNC treatment. Ideally, any intervention should adopt a more holistic, family-centred approach, which views both the patient and the carer as the recipient of care, rather than just the individual with the health condition (Hamilton, Roach, & Riley, 2003). This would involve including both patients and carers in any pre-treatment education regarding the potential impacts of treatment on the communication subsystems, and the likely implications of those changes. Further to this, there is a need for evidence-based interventions that specifically target the psychosocial adjustment of both HNC survivors and carers, to the communication changes associated with curative chemoradiotherapy. This role will largely fall to the speech-language pathologist. However, other members of the multidisciplinary team should remain cognizant of the need to refer to speech-language pathology if communication difficulties arise at any stage of HNC management. This is an area for future research.

Though the current study has provided unique insights into HNC survivors' and carers' experiences of communication changes following chemoradiotherapy for non-glottic HNC, some limitations are acknowledged. Both HNC survivors and their carers were interviewed using a reflective approach when commenting on their past and ongoing experiences with regards to communication changes. No distinction was made between early and long-term post-treatment experiences and therefore, the current findings are more representative of the ongoing experience, rather than determining the extent of the impact and the individual adjustment at various time points. Future studies may choose to conduct in-depth interviews at regular time points throughout the post-treatment period to allow for prospective data analysis, thus enabling a more accurate reflection of the critical time points

in the post-treatment experience. In addition, quality of life was not explicitly measured in this study, and therefore the extent to which the communication changes affected the participants' overall quality of life could not be quantified. Finally, although maximum variation sampling was used to highlight central themes across a variety of participant variables, the recruitment was conducted through a single clinical service, and therefore the participants' experiences may not be representative of all survivors of HNC and their carers.

### **Conclusion**

The current study has provided a unique insight into the lived experiences of communication changes following chemoradiotherapy for non-glottic HNC from the perspective of both HNC survivors and carers. The themes to emerge from the qualitative interviews highlight areas to address in the post-treatment care for both HNC survivors and their carers. Health professionals should consider the impact of communication changes on the everyday lives of HNC survivors and their carers, and provide adequate and timely education and management to this population. Providing interventions which adopt a holistic and family-centred approach to communication management may be most beneficial for to achieve positive long-term outcomes for whole family unit living with the effects of HNC management.

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### **Declaration of Interest**

The authors report no conflict of interest. The authors alone are responsible for content and writing of paper.

Table 1

Demographics of head and neck cancer survivors and carer participant groups

Demographics	Parameters	HNC Survivor Participants (n=14)	Carer Participants (n=9)
Age (years)	< 65	11	9
	≥ 65	3	0
Gender	Male	12	1
	Female	2	8
Time since treatment	< 3 months	3	2
	> 3 months	11	7
Geographic location	Major City	12	8
	Regional/Rural/Remote	2	1
Employment status	Employed	9	6
	Retired/Unemployed	3	3
	On Sick Leave	2	0
Primary site	Tonsil	7	
	Base of Tongue	4	
	Nasopharynx	2	
	Hypopharynx	1	
Tumour stage	T0-2	9	
	T3-4	5	
Nodal stage	N0-1	3	
	N2-3	11	
HPV status	Positive	8	
	Negative	1	
	Unknown/not tested	5	
Smoking status	Never	5	
	Ex	9	
Alcohol Consumption status	Never	3	
	Ex	4	
	Current	7	

*Note.* HPV = Human papillomavirus; T = tumour; N = nodal stage

Table 2

## Theme 1: Impairments in communication subsystems

Categories	Example quotes from HNC survivors (n=14)
'My voice is different' [P014]	<i>'There will come a point where it [voice] just gives up the ghost and it goes back to this [rough voice]. That still happens a year after treatment.'</i> [P009]
'My mouth is so dry I can't speak' [P001]	<i>'I knew that once I started talking my mouth would dry out and then I'd start lisping.'</i> [P006]
'I can't hear properly' [P014]	<i>'My communication is affected by my hearing impairment'</i> [P012]
'The words come out funny 'cause of the [missing] teeth' [P011]	<i>'If I try and say 'tree, tree, number three' ... it's not the same because you haven't got teeth...[it's] embarrassing'</i> [P011]
Changes noticeable to survivor but not others	<i>'On the speech side...this concerns me... the letter s sounds very /sh/. Other people don't necessarily notice it'</i> [P001]

*Note.* HNC=head and neck cancer

Table 3

## Theme 2: The challenges of communicating in everyday life

Categories	Example quotes from HNC survivors (n=14)	Example quotes from carers (n=9)
'People don't understand' [P012]	<i>'Your greatest enemy is the people who should be [your] greatest advocate. They don't realise that they're not being inclusive' [P012]</i>	
Lack support for communication from health professionals	<i>'They didn't want to start doing any [voice therapy] with me ... I'm very stubborn so I just started doing stuff on my own.' [P009]</i>	<i>'I don't think there's a lot of support there for carers' [C002]</i>
'It's all too much trouble' [P012]	<i>'[My wife] will say something while she's facing somewhere else and then I haven't heard. The she'll say ***** don't worry.' [P012]</i>	
'With background noise ... it's a lot harder for me to hear stuff' [P019]	<i>'As a result of [background noise] you tend to disengage and they tend to disengage and won't talk to you' [P012]</i>	

*Note.* HNC=head and neck cancer

Table 4

## Theme 3: Broad ranging effects of communication changes

Categories	Example quotes from HNC survivors (n=14)	Example quotes from carers (n=9)
Impact on communication interactions	<i>'...because of me [sic] voice and everything, I have stopped talking as much. I have just cut back on me [sic] talking.'</i> [P022]	<i>'You can tell his mouth is dry and it's hard to understand what he says'</i> [C007]
Impact on family interactions	<i>'[My family] don't ask me as many questions as what they used to. They don't seem to talk to me as much.'</i> [P014]	<i>'I felt that he had removed himself from family life and he didn't communicate, maybe because he couldn't.'</i> [C005]
Impact on work	<i>'I don't like to stand up in front of everyone and makes speeches anymore ... it definitely changes your life'</i> [P011]	
Impact on social interactions	<i>'I just don't talk as much and I don't go out'</i> [P022]	<i>'Socialising and in large groups, like parties, is very, very difficult'</i> [C016]
Emotional responses to communication changes	<i>'I don't hear the phones ringing sometimes and it's frustrating'</i> [P012]	<i>'It is frustrating because you say things many, many times'</i> [C016]
It hasn't stopped me from communicating	<i>'it doesn't stop you from talking, it might slow me down for a couple of minutes'</i> [P008]	<i>'... it doesn't stop us going to the movies or going out to dinner'</i> [C011]

Note. HNC=head and neck cancer

Table 5

Theme 4: Adaptations as a result of communication changes.

Categories	Sub-categories	Example quotes from HNC survivors (n=14)	Example quotes from carers (n=9)
Behavioural strategies	Relieve dry mouth	<i>'I need to make sure I've got a water there to be able to talk to people'[P009]</i>	<i>'I had to push him to drink water' [C007]</i>
	Compensate for voice changes	<i>'I have to have a decent warm shower with steam'[P009]</i>	<i>'He'd get on the phone and he'd lose his voice. I'd say 'don't worry about it, I will just answer the phone for you''[C013]</i>
	Compensate for hearing changes	<i>'I'll have to confirm with them otherwise they won't know I've heard'[P012]</i>	<i>'[You] have to repeat yourself'[C012]</i> <i>'I have to make sure he is watching me'[C016]</i>
	Non-verbal techniques	<i>'I can ... read lips to a degree' [P019]</i>	<i>'I would like to pursue the Auslan classes'[C016]</i>
	Technology	<i>'I've got these earphones now that I can put on that have my own volume adjustment'[P012]</i>	<i>'Technology for the hearing ... we have done a lot of our own research'[C016]</i>
Emotional adaptation	Acceptance	<i>'my life now is part of the compromise because it can't be the same as it used to be' [P001]</i>	<i>'I have no choice, I have to work on it [communicating] otherwise it is going to fail' [C016]</i>
	Hopeful for future improvement	<i>'Now hopefully all that [speech] improves, but remains to be seen' [P006]</i>	<i>'I always figure everything will be alright' [C005]</i>
Support	Family/friends	<i>'the family understands that I couldn't talk on the phone' [P024]</i>	<i>'having a good support friend ... I would hate to think of the result without her' [C006]</i>
	Other HNC survivors/carers	<i>'Week 1 you'd talk to the week 4 boys ... and they would talk to the</i>	<i>'I actually got involved with Cancer Council as peer support because</i>

*week 7 and you'd get  
advice off them.'*  
[P022]

*there wasn't a lot  
available to us' [C011]*

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*Note.* HNC=head and neck cancer